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ABSTRACT

This monograph presents nine author-contributed papers which look at issues of aging and mental retardation from the perspectives of nine nations: Australia (by Trevor R. Parmenter), Great Britain (by Steve Moss), Canada (by Gerrit Groeneweg), Germany (by Gottfried Adam), Hong Kong (by John W. L. Tse), Indonesia (by D. Lianta), Japan (by Takeo Kanetsuki), the Netherlands (by Meindert J. Haveman and Marian A. Maaskant), and Singapore (by M. K. Wong). A concluding paper by the editor notes three predominating philosophies of service welfare: the Asian model (with its emphasis on family care through the extended family); the Western European model (with institutional care a major component); and the North American/United Kingdom model (characterized by a strong philosophy of normalization and deinstitutionalization). Other conclusions suggest that most countries have adopted a largely voluntary sector organization supported from government finance and that all these countries recognize the urgency of developing policies and services for the increasing numbers of older persons with developmental disabilities. An American perspective on the issues is provided in commentaries by seven American authors. Most papers include references. (DB)

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AGING AND DEVELOPMENTAL DISABILITIES: PERSPECTIVES FROM NINE COUNTRIES

Steve Moss, editor

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Monograph #52

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Great Britain

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Australia

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D. Lianta
Indonesia

Takeo Kanetsuki
Japan

Meindert J. Haveman
and Marian A. Maaskant
The Netherlands

M. K. Wong
Singapore

with commentators
United States

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Preface and Acknowledgements

The topic of this IEEIR Monograph (#52 in a series of monographs published through grants received since 1978 from the National Institute of Disability and Rehabilitation Research) is dedicated with love to Rosemary and Gunnar Dybwad whose extraordinary efforts and dedication for fifty years in the field of international mental retardation are unmatched. This monograph on Aging and Developmental Disabilities is on a topic which has gained international attention in the past few years, thanks, in part to, Matthew Janicki and Marsha Seltzer who coordinated and convened a Boston Roundtable on Research Issues and Applications in Aging and Developmental Disabilities in November 1990 to which researchers from around the world came. This meeting was held in recognition of 1) the need to acknowledge the increasing longevity of persons with mental retardation resulting from more readily available services and improved health care; 2) the increased visibility of persons with mental retardation aging in the community instead of in institutions; 3) the desire to know how all this is playing out on a worldwide scale.

The IEEIR was invited to participate and also helped to fund a participant from Australia, Trevor Parmeter, to attend that meeting. We also met with several international experts including Steve Moss and James Hogg with whom we discussed the possibility of doing a publication.

Through the assistance of many individuals including the Dybwads, Moss and Hogg made contacts with potential authors in Asia and the Pacific Because Hogg took on a new position, leaving the Hester Adrian Foundation at the University of Manchester in England, he was unable to continue in his role as co-editor. We are extremely grateful to Steve Moss for persevering in the endeavor. We feel the outcome is well worth his extraordinary efforts as primary editor.

Regular IEEIR readers know that one of the primary project activities of the IEEIR is to publish monographs on topics of interest in the disability field that are written by foreign authors. Not only is there much to be learned from other countries which can enrich the knowledge base in the disability field in the U.S., but also there is much to be learned from the experience of being a "learner," or from understanding that the U.S., a country which has shared its expertise with the rest of the world, can also benefit from "listening" to and learning from what other countries are facing and how they are responding to disability needs and issues. What we "hear" when we "listen" comes to us out of the experience of another culture. Some of what we hear may be unsettling so it is important to key into different cultural contexts.

It is a primary goal of the IEEIR to expose readers to other cultures, not for evaluation but to increase cultural awareness. For example, our interest may be aroused when we read at the end of the Hong Kong chapter in this book that there is a need to identify the elderly developmentally disabled population so they can be provided with the services they are entitled to. Some would object to this approach and would possibly assume that these folks must already be integrated into society if they have not been identified as old and developmentally disabled and thus should not be labeled and thus stigmatized. However, they might actually be living in very restricted circumstances where provision of age-related services (or disability- related services, for that matter) might make a very positive difference in their lives.

Because it is our practice to include U.S. reaction to the material written by foreign authors in our publications, U.S. specialists on the topic being written about are asked to comment on the material and to put it into a U.S. context. Since under the IEEIR project design, these publications are intended for distribution in the U.S., commentaries from a selected group of specialists provide another dimension which has proved in the past to be both informational and stimulating. Different points of view are not only welcomed, but are encouraged.

We wish to acknowledge the participation in the preparation of commentaries from the U.S for this IEEIR monograph of Bruce Blaney, Susan Frankel, Marsha Seltzer, Evelyn Sutton , Ruth Roberts, Matt Janicki, and Louis Rowitz, a few of the individuals in the U.S. who are contributing to the field of aging and developmental disabilities in various ways that build on the work of Rosemary and Gunnar.

Diane E. Woods,
IEEIR Project Director
October 1992

Foreword

Aging and Developmental Disabilities- An International Perspective from Nine Countries is a welcome addition to the professional literature in our field. As I have discussed elsewhere (Dybwad, 1985), one of the glaring misperceptions of early studies as well as in practice was that of the mentally retarded person as the eternal child.. It was not until the 1960s that there was even a beginning of public and professional recognition that people with mental retardation did indeed grow into adulthood. It was in 1960 that the Woods School Conference: "Outlook for the Adult Retarded" took place which included a reference to "the challenge of aging persons with mental retardation" (Dybwad, 1960).

Internationally, it was at the 12th Congress on Gerontology convened in Hamburg, Germany in 1981 where for the first time a full session on "The Aging Mentally Retarded" was presented. In fact the president of the Congress that year, Hans Thomae, Professor at Bonn University, himself the parent of a mentally retarded person, along with his wife, Ingeborg, had been asked three years earlier to chair a task force on aging for the International League of Societies for Persons with Mental Handicap.

Since 1981 considerable research has been done in the field of Aging and Mental Retardation in the U.S. by scholars such as Marty Krause, Marsha Seltzer, Matthew Janicki as well as the staff of the consortium of the Research and Training Center on Aging and Developmental Disabilities in Akron, Ohio.

The information in this IEEIR monograph, deftly pulled together and edited by another important scholar in the field, Steve Moss from the UK, from nine countries widely dispersed by geography, economic and cultural factors, provides a basis for significant comparisons and the stimulation for even more cross-national studies and awareness building related to the needs of persons with developmental disabilities across the lifespan.

Rosemary and Gunnar Dybwad, August 1992

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The Authors and Their Affiliations

Gottfried Adam
Institut für Religionspädagogik
Evangelisch-theologisch Fakultät
Rooseveltplatz 10
A-1090 Wein, Austria

Dr. Gottfried Adam is presently teaching at the University of Wuerzburg, Germany.

Gerrit Groeneweg
Executive Director
The Vocational & Rehabilitation Research Institute
3304 - 33rd Street, N.W.
Calgary, Alberta, Canada T2L 2A6
and
Adjunct Professor, Department of Psychology
The University of Calgary, 2500 University Drive N.W.
Calgary, Alberta, Canada T2N 1N4

Meindert H. Haveman
and
Marian A. Maaskant
Department of Epidemiology/Health Care
University of Limburg
P. O. Box 616
6200 MD Maastricht
The Netherlands

Takeo Kanetsuki
Director, Mizunokiryoh Shohkaen
12 Shimogolan Kawarabayashi
Kameoka 621
Kyoto, Japan

Dharmana Lianta
Yayasan Bhakti Luhur
P.O. Box 56
Malang Jawa Timur, Indonesia

Steve Moss
Senior Research Fellow
Hester Adrian Research Centre
The University
Manchester M13 3PL
Great Britain

Trevor Parmenter
Associate Professor
Unit for Rehabilitation Studies
School of Education
Macquarie University
New South Wales
2109 Australia

John W. L. Tse
Sr. Lecturer of Psychology
Department of Applied Social Studies
Faculy of Humanities & Social Sciences
City Polytechnic of Hong Kong
83 Tat Chee Avenue
Kowloon, Hong Kong

M. K. Wong
80, Southbridge Road
Singapore 0105
M. K. Wong Vice President, Association for Educationally Subnormal Children, Singapore.

U.S. Contributors

Bruce C. Blaney
Human Services Research Institute
Cambridge, MA 02140

Gunnar Dybwad
390 Linden Street
Wellesley Hills, MA 02181

Susan L. Frankel
Director, Social Data Center
Institute for Policy and Social Science Research
University of New Hampshire
Durham, NH 03824

Matthew P. Janicki
NYS Office of Mental Retardation & Developmental Disabilities
44 Holland Avenue
Albany, NY 12229-0001

Louis Rowitz
Associate Dean for Academic Affairs
School of Public Health
University of Illinois at Chicago
Chicago, IL 60680

Marsha Mailick Seltzer
University of Wisconsin
Waisman Center
1500 Highland Avenue
Madison, WI 53705

Evelyn Sutton
University of Akron
Institute for Life-Span Development and Gerontology
179 Simmons Hall
Akron, OH 44325-4307

CHAPTER ONE
An Australian Perspective

by Trevor R. Parmenter

National Background

Size of country and population

The vast Australian continent (77 million square kilometers) is populated by approximately 17 million people - nearly 65 per cent of whom live in the capital cities of the six states and two territories. The majority of the population lives in two coastal regions, the largest along the south eastern seaboard and the smaller along the south western coast. Almost three quarters of the Australian land mass is relatively uninhabited.

There is disagreement in Australia as to how many persons with intellectual disabilities are aged and elderly. A recent report of the Australian Bureau of Statistics (McLennan, 1990) indicated that in 1988, 15.6 per cent (2.5 million) of the Australian population had a disability, and 13.0 per cent (2.1 million) were handicapped. The report further indicated that approximately 0.7 per cent (112 thousand) of the population had an intellectual disability.

The scope of the 1988 Survey covered both rural and urban geographical areas in all states and territories of Australia, and both private and special dwellings. Private dwellings were homes, flats, home units, garages, tents and any other structures used as private places of residence at the time of the survey. Special dwellings were hotels, motels, hostels, boarding houses, hospitals and nursing homes, educational and religious institutions, construction camps, and caravan parks.

Division of Population

The division of the population according to disability, handicap and severity of handicap is illustrated in *Figure 1*.

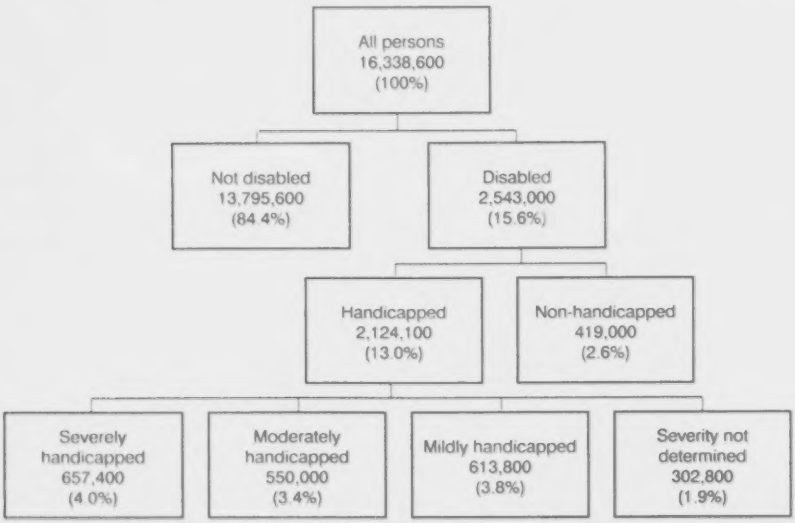

Figure 1. All persons: Number and percentage of population who are disabled or also handicapped by severity of total handicap. (Castles, 1989)

Need for and receipt of help

The need for and receipt of help by both disabled and non-disabled aged people differed little between those living alone and those living with other people. Of the 2,357,600 people aged 60 years and over living in households, 1,037,200 were disabled and 1,320,400 were not disabled. Seventy-three per cent of those disabled and 40 per cent of those not disabled needed help with at least one activity. Females more frequently reported a need for help in both the age groups (disabled and non-disabled). Eighty-seven per cent of disabled aged females needed help, while 60 per cent of disabled aged males needed help (Figure 2).

The classical aging patterns of aging persons with an intellectual disability that result in a slow decline of functional abilities and cognitive functioning affects this population in a similar manner to other older people. The majority of clients over 60 years of age have a mild to moderate level of disability. Approximately

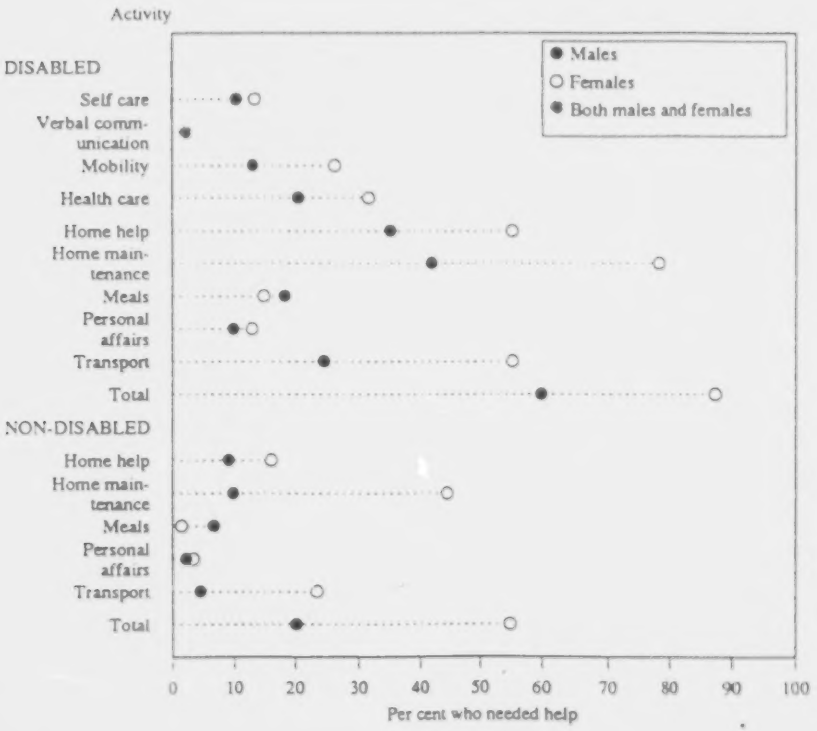

Figure 2: Disabled and nondisabled persons aged 60 years and over living in households. Activities for which help was needed, by sex, Australia, 1988. (Castles, 1989).

one-third of this population has been identified as having a behavior management problem.

The self care and social skills of people living in the community are generally

higher than those who reside in training centers. The majority of older people with an intellectual disability have limited skills in the areas of independence, community awareness and domestic/household management.

General Background To Welfare Services

Structure/Organization

Australia has a federal system of government with the six individual states and two territories having their own legislatures; a situation somewhat similar to Canada and the United States. However, the Australian parliamentary structures are based upon the British Westminster system.

The demographic revolution of the twentieth century in the developed world has meant that mainstream adults are living longer and special populations are surviving in ways not previously experienced nor planned for. Adults with intellectual disabilities are outliving their parents or are aging along with parents in two-generation geriatric families.

Services for persons with developmental disabilities who are aging are delivered in three main ways: through informal care from relatives, neighbors and friends; through the formal networks of community services provided through non- government agencies; and through services provided by the three levels of government: local, state and commonwealth.

Services for aged people with a developmental disability are currently interwoven with services for all older people within the community. Issues in the development of community services recently identified in a Green Paper published by the state government of New South Wales (*Directions on Ageing in New South Wales*, 1989) include Government Budget Implications, the Role of Carers, the Role of Volunteers, Information and Access to Services, and User Rights.

Only recently has the commonwealth government recognized the problem of the aging intellectually disabled group of people in the community by its commissioning of a national survey of their needs by the Schonell Special Education Research Center at Queensland University.

General Information On Services

National and regional policy/philosophy

The federal government is the major funding body for nonprofit organizations that conduct residential and vocational programs for people with moderate to mild levels of disabilities in all states and territories. At the federal level a major legislative initiative has been the introduction of the Disability Services Act of 1986. This Act is responsible for sweeping changes in the type of residential and vocational services where essentially no new service will be funded that is not community-based. Traditional service types have until 1995 to submit a detailed plan of their transition to regular housing and community integrated day and work programs.

All state governments and territories have provided residential programs for those with a severe disability, historically through departments of health, but more recently under the aegis of departments of community services. All states are engaged in programs to move these people from hospital environments to community-based accommodation in regular homes, flats or units. In most cases this movement has been particularly slow.

The NSW *Directions on Ageing Papers* that relate to the general elderly population are based on three primary assumptions; older people live mainly in urban centers; older people have special housing requirements, and the needs of older people vary greatly. Goals and action priorities include: fostering a positive public image of older people, protection against age discrimination, encouraging a greater emphasis on health promotion, ensuring the development of appropriate care and accommodation options, and maximizing opportunities for older people in employment, social and recreational activities, and community contributions.

At neither the commonwealth nor state levels are there any statutory provisions for aging people with an intellectual disability.

The pattern of services in Australia for people with a moderate to mild level of intellectual disabilities vary from special to integrated school services at the childhood level, from sheltered to open employment options; and from living in the parental home to various forms of semi-independent living. Within sheltered employment the tendency has been to keep people employed well beyond the average retirement age for the non-disabled population, especially if they continue to be productive. Until recently no concerted efforts were made by service organizations to provide alternative day activities.

For those more severely intellectually disabled, day programs were provided in Adult Training Centers. Many of these were and continue to be "low level" sheltered workshops with few financial resources to employ specialist staff that could offer a more relevant and rewarding program. In many cases even these facilities have turned away many people with severe multiple disabilities, the alternative being either a nursing home environment or staying in the parental

home.

Both commonwealth and state governments are presently exploring ways to provide a more meaningful program for this group (Parmenter, Briggs, Gray and Knox, 1990). It has yet to be recognized in Australia, at least in some tangible way, that there may be a need for special efforts to assist people with an intellectual disability to make the transition from work to full-time leisure. It is suspected that this issue has not been addressed as the commonwealth government, through its Disability Services Act (1986), has been at pains to emphasize the value of "real" rather than sheltered employment. Despite vigorous efforts since 1986 to encourage the development of supported and competitive employment programs, they still only cater for less than five per cent of the intellectually disabled population. As these programs expand and as the growing consumer rights movement spreads throughout the sheltered workshop network, issues such as retirement benefits will be focused upon.

Intellectual Disability and Aging: A Study

One study specifically addressing the needs of people with an intellectual disability who are aging in Australia was commissioned by the NSW Council for Intellectual Disability. This was a study of a group of thirty people with an intellectual disability who were adults living at home (NSW Council for Intellectual Disability, 1989).

Many of the issues and recommendations emerging from the study overlap and address the needs of both the persons with a disability and their families and/or carers.

The Eternal Child

Most families did not consider that their adult relative with a disability would be able to achieve independence; they perceived their relatives as "eternal children" with childlike needs, especially the need to be protected. The most commonly expressed fear was that their relative would be vulnerable to sexual advances/assault. They also feared that in a community placement their relative would be exposed to a life-style of which the carers or the family might disapprove. They were concerned that the supervision they required would not be forthcoming in most community placements.

Information

A lack of information, understanding, and the use of Government services was indicated by the people with disabilities, their carers, and by service providers. A need for identification of the individual needs of people with disabilities was highlighted.

Support Services

A support service was seen as necessary for carers of people with intellectual disability. The Home and Community Care (HACC) program (see Appendix) was seen as having to address the needs of this group of "invisible" people. It was suggested that the present priority that is given to organizations making demonstrable efforts to address the needs of the HACC program may have disadvantages for those families whose only support services may be organizations providing traditional services, such as long-term placements or workshop activities.

Carers

It was usually a female carer who was responsible for the care of their relative. Many of the aging mothers were caring not only for an adult relative with an intellectual disability, but also for an ill or invalid spouse. Many voiced their concern at the need to undertake a "fund raising" or other activities for the service organization which provided an activity center for their adult child. Many indicated that they found the caring role stressful, with little or no relief from this role. Their priority was for the establishment of a support network to be made available for all carers of people with an intellectual disability who live at home.

Accommodation

A major finding of this study was the current unavailability or inadequacy of suitable accommodation options for older people with intellectual disability who have resided with their parents/families. Many families found that the services which had provided for their relative when they were younger were no longer available. Many families had plans to undertake original schemes in order to provide for their relative, but these plans had in many cases been unable to be realized owing to lack of an appropriate range of models of care, or of facilities and services.

Service Provision

The families interviewed indicated that they did not understand the Home and Community Care program provided by the Government and many service providers did not have sufficient information of the services available. Also, there was a pressing need for a variety of respite care arrangements for adult people with intellectual disabilities and their carers.

The Future

Very few families had been able to make realistic arrangements for the future care of their relative and thus, at present, many of these elderly people will be placed in care as a result of family crisis. Most care providers interviewed were anxious about the quality of their extended family to cope in the future. Future planning was not possible because of the unavailability of adequate accommodation and other services, and the Home and Community Care Services was not considered a part of their future management plan.

Recommendations

• The NSW Council for Intellectual Disability, together with other disability groups, should lobby the Federal Government to include disability as an integral part of the National Census, rather than conducting a specific census on disability that suffers from sampling errors.

•The Council should establish its own data collection system which would be compatible with statistical classifications contained in other significant systems.

•A range of appropriate accommodations should be available for this group of adult people with an intellectual disability, affording adequate care and protection. There should also be recognition that some people with a disability may be unable or unwilling to undertake independent living skills learning.

•There is a need for a campaign of information dissemination and education about the use of Home and Community Care services for this group and other disability service providers.

•A campaign should also be mounted to educate and disseminate information targeted towards Home and Community Care service providers about the special needs of aged developmentally disabled persons.

•A support system should be available to the carers of people with an intellectual disability who live at home.

•An expanded range of accommodation should be available for this group of people with exploration of alternative models of arranging for their future care.

•A major need of this population is the availability of a range of suitable respite care services.

•The NSW Council for Intellectual Disability, in conjunction with other groups, should lobby to ensure that the accommodation needs of aged developmentally disabled people be recognized and addressed.

While this study has provided some very useful information concerning a small sample of people with an intellectual disability, it is difficult to draw general conclusions concerning the extent of the problems.

Options and Life Circumstances: A Survey

Current problems and future developments

A study to investigate the life circumstances of people with an intellectual disability who were aging was carried out in Queensland, Australia (Ashman, Hulme, and Suttie, 1990) and included participants in rural and metropolitan areas. The fifty subjects had an intellectual disability as their primary disability and were over the age of 50 years.

Results indicated that the circumstances of many of the participants reflect a policy of normalization and expansion of quality of life options which were available within the community. Differences were highlighted in life circumstances of people living in the two locations. In the rural setting all subjects were part of a family infrastructure with fifty per cent living at home and the remainder having a close relative near by. Proportionately, people in the rural setting appeared to live more normalized lives than those in the city with regard to access to, and participation in, activities in the community. Long term residents of city facilities generally possessed fewer independence skills than their rural contemporaries needed to facilitate community involvement.

Participation in recreation and leisure activities was largely determined by the subjects' competencies and availability of programs and services. In most cases, involvement in community events meant organized group activities such as an Activity Therapy Center where craft activities were the main focus.

Low levels of socialization were highlighted across urban and rural locations, for instance: social interactions with others in the place of dwelling was the most basic level of participation; no friendships or neighbor contact was reported outside their immediate residential setting.

In general, the overwhelming majority of subjects were fully mobile. Access to community resources and facilities was a function of the individual's physical condition, their intellectual capabilities and the extent to which carers facilitated access. The level of self-help skills appeared similar across geographical groups; the majority were independent in eating, dressing and in maintaining personal hygiene. Communication skills varied greatly. Health problems appeared to be similar to those reported in other research of the general elderly population. In rural areas the availability of therapy and paramedical services was an expressed concern.

The financial circumstances of the participants was difficult to establish. The general indication was that all participants were receiving a pension. Pension checks were paid into trust accounts from which "pocket money" was provided each week. In the majority of cases, carers or staff handled the participants' financial affairs.

The results of this survey indicate differences in city and rural regions and

the limited range of options available to aged persons with intellectual disabilities. The researchers suggested improving the physical conditions and the regime under which these people live. In particular, determining the minimum functional literacy and numeracy skills required by aged persons, providing more contact with other people living in the community, classifying the most appropriate community services available and the changes needed to access them, and identifying factors which facilitate successful transition from work to retirement.

Towards policy for senior persons with an intellectual disability: An Investigation

In Western Australia an investigation was conducted to examine three questions: to what extent aged persons with an intellectual disability were "at risk", were their needs similar or different from other aged persons, and did they have, or engage in, a valued life style? (Sanderson, 1991).

Subjects included 129 people who were over the age of 55 years and who lived in hostels or the community. Four risk categories were established. Seven broad areas of need were specified to assess quality of life including accommodation, day occupation, leisure, social/emotional contact, spiritual involvement and health.

Results indicated that 47 people (48 per cent) of the clients were considered to be "at risk" and required short-term intervention, while 22 people (25 per cent) had unsuitable accommodation.

The report recommended that priority should be given to assist family carers and that representations be made at commonwealth, state and local government levels where planning for the aged is currently occurring to ensure that a more coordinated national approach be adopted for developing future policies and services.

Conclusion

In recent years Australian state and federal governments have conducted enquiries into the needs of people with intellectual disabilities. At the state level reports have led to specific legislation being enacted that has prompted the gradual movement of these people out of institutional care. In addition, a number of states have enacted guardianship legislation to protect the rights of these people.

However, the specific needs of aged persons with developmental disabilities in Australia have not been adequately addressed. Quality of life issues that include aspects such as empowerment, satisfaction, decision-making, independent living,

social and interpersonal relationships, activity patterns, socio-economic factors, and physical and psychological access to community services, should be explored in the context of the environments in which these people live (Parmenter, 1988).

A national database must be established, first, in order that we know who, where and what are the current numbers, ages, and needs of aged persons with intellectual disabilities and, secondly, what are the characteristics of current provision of services for this population. The limited data that are available tend to confirm trends found overseas, that aged persons with intellectual disabilities are a small, but increasing group, many of whom are not in receipt of adequate services. The determination of the size and geographical distribution of this population across Australia is a challenge that must be met.

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Appendix I: Home and Community Care (HACC)

The Australian commonwealth and state/territory governments jointly fund Home and Community Care (HACC). These funds are made available to state authorities, local government bodies and non-profit community and volunteer organizations for the provision of the support services. Both the commonwealth and state/ territory governments determine the policies and priorities for HACC. The state/ territory administrators are responsible for day-to-day management.

HACC provides a range of support services to people in their own homes or in a nearby community center. The services aim to be flexible, to allow for individual needs - whether they need one or two services or several.

Personal care services may be available to assist in activities such as bathing, dressing, eating, toileting or other personal tasks. Trained people can visit to help with or teach independent skills. • *Home Helpers* assist with general housework such as cleaning, laundry and, in some cases, cooking. • *Respite services* give carers a break. They can also be used to give someone with a disability a break from their normal routine. Respite care may be provided in a home or in a day care center or community center. • *Home maintenance and/or modification* can help maintain a home, both for safety and security. Replacing tap washers and light bulbs, mowing lawns and pruning trees are typical home maintenance chores. Minor modifications such as fitting hand rails, may also be carried out. An advice and referral service to either voluntary or paid maintenance may also be available. • *Food services* may be provided through Meals on Wheels. Shopping services arrange for someone to purchase food and other requirements and deliver them to the home.

• *Paramedical or allied health* includes physiotherapy, podiatry, speech therapy and occupational therapy. These services, which may be available in the home or at a community center, may assist in maintaining independence and mobility • *Community or domiciliary nursing* can help improve or maintain health and well-being. Trained nurses provide this service in the home or at a

community center, on either a short or long-term basis. Community nursing can be coordinated with local home care organizations, doctors, hospitals and other agencies. Assistance with incontinence is also often available.

• Transport services can help if it is impossible to use community transport. They include mini bus services, shared-ride taxis or hire cars, taxi voucher systems, dial-a-bus services or volunteers who will drive persons to appointments in their own cars. A fee may be charged for some services, however, services will not be refused due to inability to pay.

The HACC program makes it possible for many people with disabilities to live in their own homes by helping them to help themselves with personal care, house-keeping and getting around the community.

Acknowledgment: The assistance given by Barbara Kearney to the development of this paper is gratefully acknowledged.

CHAPTER TWO
A Perspective From Great Britain

by Steve Moss

General Background To Welfare Services

Public expenditure on long-term care for people who are elderly, mentally ill, developmentally disabled or physically handicapped, excluding the cost of acute hospital care and GP services, amounts to between five and six billion pounds annually. (*See Table 1*). About 1.5 million people receive some degree of support every year, ranging from an hour or two of home help each week, up to twenty-four hour long-term care. Of these, one million are aged over 65, and half a million are younger people who are either developmentally disabled or

Table 1. EXPENDITURE BY CLIENT GROUP (£Millions), 1984-85

	Elderly	Mentally Handicapped	Mentally Ill	Younger Disabled	Total
National Health Service	£ 1,060	500	1,090	50	2,700
Personal Social Services	1,380	320	60	140	1,900
Social Security	460	30	10	190	690
Total	2,900	850	1,160	380	5,290

physically handicapped or require long-term support following mental illness (Audit Commission, 1986).

Community care is the responsibility of three separate Government departments; Department of the Environment, Department of Health and Department of Social Services. At a District level, social services are administered by local government (Local Authorities). Health services are organized at both Regional and District level, England and Wales being covered by fifteen Regional Health Authorities, divided into Districts of about 250,000 people. Generally speaking, health and social service organizations are relatively autonomous with little administrative overlap.

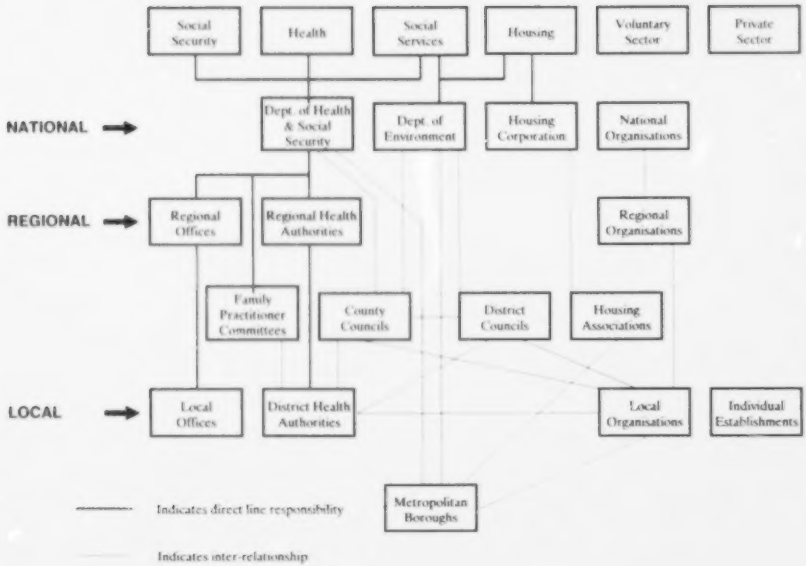

Figure 1. Principal agencies involved in community care, (Audit Commission, 1986)

Figure 1 shows the range of services provided by the main agencies involved in the provision of community care, while *Table 2* indicates the complexity of interaction between principal agencies involved in community care. Residential care is often administratively simpler because it involves only one agency. Thus, the Health Authority is responsible for hospitals, while other forms of care such as nursing homes and residential homes can be provided by any of the agencies (Health, Voluntary, Private, or Social Services). In contrast, community care usually involves services from a number of agencies at the same time, in addition to informal support from family and friends. For example, an individual may be housed in sheltered accommodation provided by the Local Authority's Housing Department, attend a Day Center run by Social Services, and receive visits at home from Social Service home helps, Health Authority nurses, and Voluntary Sector care attendants.

The lack of contact between Health and Social Services has in the past led to problems concerning the resettlement of individuals from institutions into the community. Basically, the Regional Health Authorities have had to set plans for closure of hospitals (Developmental Centers), while it is the Local Authorities who have to develop the new services in the community to accept these individuals.

Table 2. Main care and accommodation services (Audit Commission, 1986)

AGENCY	FORM OF CARE	SERVICE	VARIATIONS
Health Authorities	Hospitals	- In-patients	-Long-stay -Short-stay/respite
		- Day	
	Residential	- Community Units - Nursing homes	
	Community Services	- Nurses	- Qualified - Auxiliary
		- Health visitors	
		- Therapists	- Physiotherapists - Chiropody
Family Practitioner Committees	Primary Health Care	- GPs - Nurses - Dental and opthalmic services	
Social Services	Residential	- Residential homes	- Long-stay - Short-stay/respite
	Accommodation	- Staffed group homes - Unstaffed group homes - Sheltered lodgings	
	Day Care	- Workshops - Day centres - Training centres - Drop-in centres	
	Domiciliary	- Social workers - Good neighbours - Home helps - Therapists	- Occupational
Housing Authorities	Housing	- Sheltered housing	- Wardens - Alarm systems
		- Hostels - Group homes	
		- Flats/houses	- Improvement grants
Education	Training facilities for adults		
Voluntary Sector and Housing Associations	Residential Housing	- Residential homes - Group homes - Sheltered housing - Flats/houses	- For special needs
	Day Care	- Luncheon clubs - Drop-in centres	
	Domiciliary	- Care attendant schemes - Volunteers/good neighbours	
Private Sector	Residential	- Nursing homes - Residential homes	
	Housing	- Sheltered housing	
	Domiciliary	- Domestic agencies	

Regional plans have sometimes not been negotiated with Local Authorities, even though they have a major impact upon them. As a result, there is the danger of discharging people into the community before adequate services have been set up. However, this is certainly not inevitable, there being some good examples of

inter-agency planning. The "All-Wales" Strategy, for instance, provided a framework for implementing community care to developmentally disabled people, in which "bridging" money was made available to develop community care services before hospital services were closed.

The recent Community Care Act (HMSO, 1991) is a major piece of legislation affecting the provision of community care. One of its aims is to bring together Health and Social Service Agencies to agree on strategic plans for community care, and on plans for individual service users. The latter involves the provision of "packages" of care tailored to the needs of the individual, the development and monitoring of which is to be overseen by the individual's assigned case manager. These new case management arrangements are to be implemented in April 1993.

As a result of this legislation, the Local Authority will thus become the main agency with responsibility for overseeing the community care of disabled and elderly people. Local Authorities will, in collaboration with medical, nursing and other interests, assess individual needs, design care arrangements and secure their delivery within available resources. Within this process, central Government expects Local Authorities to make maximum use of the independent sector, a particular emphasis being placed on expansion of the private-for-profit sector.

General Information on Services To Persons With Developmental Disability

Service policy and provision in the UK over the past thirty years has demonstrated an increasing emphasis on community care. There are, however, marked differences in both commitment to and realization of this policy throughout the country. Some Regional Health Authorities and Local Authorities have made it a specific objective to establish homes in small group houses or in relatively independent residences such as Housing Association accommodation. Elsewhere, Regional Health Authorities have been content to relocate people from large institutions into units of up to 70 beds, which have been criticized as being nothing more than "mini institutions". Generally, however, the current situation is of a general commitment to the closure of large institutions and a concomitant expansion of community services.

Residential Services

Apart from large institutions and the family home, people with developmental disabilities live in a wide variety of accommodation. As a general rule, individuals of greater functional level tend to live in more independent settings. However, some regions and districts have made a specific commitment to maintaining more severely handicapped individuals in non-congregate settings. This obviously has major staffing and resource implications.

Some residential options available in the UK are:

1. "Hostels" of varying size, with an average of probably around 30 beds. These are staffed twenty-four hours a day, and generally run by Social Services or the Voluntary Sector.
2. "Group Homes". These may be unstaffed, partially or twenty-four hour staffed, purpose-built or adapted buildings.
3. The full range of "Public Sector Housing" - i.e. houses, single flats, and sheltered accommodation.
4. "Rural Colonies". These are relatively uncommon in the UK, and viewed by many as not providing a normalized environment. They do, however, tend to be popular and have long waiting lists.
5. "Adult Placement (Foster) Schemes". These are also comparatively rare.
6. "Private Sector Accommodation", as yet relatively undeveloped in the UK in relation to people with developmental disability.

Some Local Authorities have established hostels and group homes specifically for older clients.

Day Programing

Although there are few developmentally disabled people in open employment or sheltered work placement, the majority attend Adult Training Centers (ATCs). In the past, these have sometimes focused on industrial-type work. Now, the emphasis is more on social and educational programs. Programs are usually designed to give opportunities for clients of all ages and abilities, including profoundly retarded, multiply handicapped, and aging.

Integration of developmentally disabled people into the community is a strong focus of UK service provision. Examples of integrated activities include: further-education classes held in colleges for the general population and integrated with non-retarded persons where the subject permits; holidays taken in facilities used by the general population; visits to pubs, restaurants. A high priority is given to the development of socially appropriate behavior.

Services to Older Persons

Although there has been a growing interest in the service needs of older developmentally disabled people in the UK (reviewed by Hogg, Moss and Cooke, 1988), the observed impact has not been as great as in the United States, particularly in relation to the establishing of specific services. This difference in emphasis arises partly because of differences in funding and legislation governing

service provision. In the United States, day service provision has a strong emphasis on industrial work. Many of these jobs entail a considerable amount of physical energy, making it appropriate that people should cease work at or around the conventional age of retirement, and move to some more relaxed form of life style. However, tight legislation necessitates that these individuals continue to receive day programing. Hence, a large number of age-specific programs have been set up to cater for the needs of these older individuals, while yet fulfilling the legislative requirements which ensure continued funding.

In the UK, most people in contact with developmental disability services have at least a moderate level of retardation. Adult Training Centers (ATCs) tend to emphasize educational and social activities rather than industrial production, with the majority of individuals receiving welfare benefits, some of which are means-tested. This consequently restricts their earning capacity at the ATC. There is thus a similarity between the financial status of developmentally disabled adults and people in the general population receiving a state pension. At the same time, the nature of activities at ATCs allows for a lot of flexibility with respect to age and ability. These factors, coupled with the fact that the Local Authority has responsibility for clients throughout their adult life-span into old age, means that there has been little pressure to provide services which are specifically geared to older clients. Nevertheless, Local Authorities are aware of the potential impact of increasing longevity on their service provision, many authorities having conducted surveys to determine the needs of their older clients.

For example, the following recommendations, among others, appear in a recent report by Greenwich Social Services in South London (Greenwich Directorate of Social Services, 1991).

1) Provision of appropriate activities and a quiet room at the ATC.
2) Opportunity to attend the ATC on a part-time basis.
3) Access to community social, leisure, and educational activities within the person's residence.
4) Older clients should be offered a multi-disciplinary screening assessment.
5) Care staff induction training should explore attitudes towards aging and age-related disabilities and the importance of the individual's life history, as well as staff needs for support when working with people who have failing health, are dying, or who are bereaved.
6) A program of in-service training on aging and the needs of old people should be organized for care staff working with older adults. This should cover a range of psychological, physical, medical and practical topics, with sessions led by members of the multi-disciplinary team, relevant medical doctors and nurse managers.

Age-Specific Services

Although many ATCs have no statutory retirement policy, Local Authorities are aware of the need to provide a continuum of appropriate day activities throughout the life span. Some Local Authorities provide advice and guidance on retirement, and run pre-retirement courses modelled on those available to the general public.

Pre-Retirement Courses For the general population, the sometimes abrupt shift in emphasis caused by a total cessation of work has led to the introduction of pre-retirement courses designed to aid the individual in making this transition. Evidence from the American literature suggests that many older workers would be keen for their employers to set up programs of this kind (Fillenbaum, 1971; Pyron and Manion, 1970). Modelled on this approach, some developmental disability services are now providing pre-retirement courses for their older clients. Hogg et al (1988) discuss several examples of such courses. Typical activities from one such course are:

A visit to an old people's home • a visit from a dietician • a visit from a dental hygienist • discussion of facilities for elderly people at the local library • Introduction to Age Concern (a national voluntary organization providing advice and services to the general elderly population) information • trips to the theater • making music at home • meals on wheels • Church involvement.

This list of activities fits well with the kinds of needs that old people are traditionally expected to have. In considering the needs of older people with developmental disability, however, we need to explore these issues a little more closely, to look below the surface of the "face validity" of courses modelled on those provided for the general population. In particular, we need to pose the question of whether developmentally disabled people have specific needs in old age which differ from those of their non-disabled peers. In this respect, one course organizer (Cheseldine, 1987) found that a crucial component arising in discussion with older clients is a lack of happy memories to look back on, and an inability to locate themselves in the immediate history of their local area. Reminiscence therapy (Hanley, 1984) is an established psychotherapeutic approach for elderly people. Hogg *et al* (1988) review the use of this technique with developmentally disabled individuals.

Day Services

Although there are no compelling legislative or funding reasons in the UK for the establishing of age-specific day services, a number of Local Authorities have instigated such services for reasons of administrative convenience. Hogg *et al*

(1988) describe two day centers for older developmentally disabled people, both of which were set up primarily because the local ATC was becoming overcrowded. With no formal policy of retirement, clients were staying on into their sixties and seventies, with the result that there was no space for young school leavers. On visiting these two centers, it was most interesting to see how each developed its own philosophy and raison d'etre. The fact that the centers were initially set up for administrative reasons had left open the possibility of their becoming a "dumping ground" for old people - a possibility which appeared to have become a reality in the first of these centers.

In comparison, the second of the centers reviewed had achieved a remarkable sense of community through the use of an unusual management structure; management was conducted, almost totally, by the clients themselves. At its original inception there was a fixed age criterion of fifty-five to sixty years for transfer from ATC to the elderly group. Latterly, however, the policy was to pay close attention to the needs and wishes of individual clients. Some people prefer to stay on at the ATC because they like the nature of the activities. Conversely, some people fit well in the elderly group at a much younger age than originally conceived. Overall, the activities of the older group were more likely, on average, to suit older clients, while younger people usually fit better into the ATC. This flexible age criterion was a recognition that individual needs are so variable that age can only be taken as a rough criterion.

Family Involvement

The particular problems faced by parents caring for an older developmentally disabled son or daughter was one of the broad issues explored in a major study of aging and developmental disability conducted by the author and others in the Hester Adrian Research Center. (Moss & Patel, 1992; Moss, Hogg & Horne, 1992a; 1992b; Moss & Hogg, 1989). A sizeable proportion of the sample over 40 years of age were living at home with their families (32%). The average age of these carers was 65.4 years, 60% of whom were aged over 65. This is particularly significant since well over half the sample were dependent for care on a group of people who themselves could be termed potentially "vulnerable" or "dependent". In two extreme cases the health of the main carer had worsened to such an extent that the individual with developmental disability was the one who was actually in the care-giving role.

The study demonstrated the extreme responsibility placed on the immediate family to provide day-to-day care, with other family members having little involvement. Typically, the responsibility fell to a single family member to respond to the needs of their developmentally disabled relative. The results also showed that the older the parents, the more they expressed the need for additional help with care management. This need was exacerbated by the extremely limited

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support network of many of the oldest parents.

Parental plans for the future care and financial support of their relatives were minimal. In most cases, the carers felt a long-term commitment to care for their relative as long as possible. The possibility of "crisis" resettlement due to ill health or death of the main carer thus remains highly likely.

Example of a Service For Older Developmentally Disabled Persons

The following section is a very brief resume of a detailed demographic study of people over 50 years of age with developmental disability, mentioned above. This first study was completed in 1989, results then being extended to include information on physical and mental health in a subsequent study completed in 1991 (Moss, Goldberg and Patel, 1991).

Oldham Metropolitan Borough is an industrial town of 2,225 people in the Greater Manchester area, which is included in the North Western Regional Health Authority (NWRHA). The NWRHA has developed criteria for a model District service based on the concept of an ordinary and valued life for those residents being resettled from large institutions. NWRHA hospital staff collaborate with the Local Authorities to implement the Model District Plan during residents' transitions from hospital to community.

Within the framework of the Authority's document, older people are not regarded as having special needs, although the presence of severe sensory, neurological, motor, psychiatric, behavioral or multiple difficulties would lead to the inclusion of some older people in this special needs framework. Although the Model District Plan encourages collaboration between services for people with developmental disabilities and those for the general elderly population, discharge of long-term hospital residents into old people's homes is not considered an appropriate placement.

In Oldham, the Community Mental Handicap Team (CMHT) operates as a specialist referral agency responding to individual needs, rather than providing a service to all people with developmental disability in the Borough. One consequence of this policy was that a substantial proportion of these older people were no longer in contact with the CMHT. For these individuals, the most common agencies delivering services were social work teams for the general elderly population.

Of those people in contact with the CMHT, 59% of the under sixties were still attending the ATC, but only 9% of the over seventies. People in the CMHT sample were receiving a wide variety of individual programs, day trips, visits to pubs and restaurants, etc. Generally speaking, CMHTs pursue a vigorous policy

of community involvement for clients of all ages.

A substantial majority of persons retain contact with family members, although this contact was lowest for people living independently. Contact with family members did not differ between those resident in the immediate community and those in isolated long-stay institutions, emphasizing the extent to which maintenance of the relationship depends on the initiative of the family members. Neither age, competence nor difficult behaviors had any bearing on the extent of family contact.

A most striking contrast in this population was between the 75% of people receiving services from the CMHT and those receiving services elsewhere. In the light of Wolfensberger's (1985) observations on the potentially devaluing consequences of including persons with developmental disability in generic services for elderly individuals, it is of interest to note that the group receiving CMHT services:

(a) received more individual programs related to personal and community competence;
(b) received a higher level of educational input;
(c) were more involved in community leisure pursuits and vacations.

Since the study found no evidence for major differences in functional ability between the people in contact, and out of contact with CMHT services, there had to be some other reason for these differences in service input. The most likely interpretation is a difference in the philosophies of service provision to elderly people and to people with developmental disability. Since we were not in possession of in-depth assessments of individuals' support needs, it is inappropriate to discuss the relative merits of specific service provision. Nevertheless, our findings lent support to Wolfensberger's concern regarding the use of generic services. While integration remains a valued goal with respect to service provision for older clients, the study argued for caution and careful monitoring to ensure there is no reduction in quality of services arising from these different philosophies. (Moss, Hogg & Horne, 1992a)

Future Developments

Given the autonomy of the various agencies involved in community service provision in the UK, there are likely to be variations in the pattern of service provision to older developmentally disabled people in different local authorities. Generally speaking, however, it is clear that few agencies are regarding the needs of their older developmentally disabled individuals as being sufficiently different to warrant specific provision. It should be clear to the reader that this does not represent a lack of interest in these individuals, but rather the view that their needs are better served within the framework of services to adults with developmental disability. In addition, integration of services for developmentally disabled and

general elderly people, a valued goal in the United States, has attracted less interest in the UK. Although in Britain interchange between developmental disability and elderly services presents no major legislative or funding problems, it may be that there are nevertheless attitude barriers between the two services. Also, some Regional Health Authorities have adopted Wolfensberger's view that elderly services are not a good model for older developmentally disabled individuals since many members of the general population receive an impoverished service.

One important consideration in strategic planning for services to the older developmentally disabled group is the impact of differential mortality. In the general population the majority of individuals reach old age. Many of these individuals show age-related infirmity in later life, as a consequence of which the average functional status of the elderly population is lower than for younger groups. Amongst developmentally disabled people, however, a larger proportion of people die before they reach old age. This mortality is selective, the frailer members of the population tending to die earlier. As a result, the average functional ability of a population with moderate, severe, or profound handicap actually rises with age (Moss, 1991).

Most notable is the differential mortality with respect to people who have Down's syndrome. In Oldham, for instance, we found that these individuals constituted only 10% of the 50+ population (Moss, Hogg & Horne, 1992b). These changing group characteristics with age demonstrate the importance of developing both strategic and individually based plans. Individually tailored packages of care take account of the fact that some surviving members of the developmentally disabled population will suffer from age-related problems. The high risk of Alzheimer's disease for people with Down's syndrome is a notable example; while the majority of people with Down's syndrome die before the age of fifty, many of those who live to be older will suffer from this debilitating disease, necessitating a high degree of support to the individuals and their families. Overall, however, the total support requirements for older developmentally disabled persons as a whole may be no greater than for younger age bands, since the younger age bands have a higher prevalence of other conditions requiring increased support, such as severe problem behaviors and epilepsy.

The new Community Care Act in Britain reinforces the importance of both strategic and individually based plans. It remains to be seen how far this legislation has an impact on future service provision.

To date, there are no firm answers to the question of which are the most appropriate service models for older developmentally disabled persons. Up to now, most developments in service provision have been based on philosophy rather than objective evidence. We are very much in need of studies which will explore different types of service provision and their impact upon the quality of life of the individual as he/she ages.

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CHAPTER THREE
A Canadian Perspective

by Gerrit Groeneweg

National Background

With the break-up of the Union of Soviet Socialist Republics (U.S.S.R.) in 1991, Canada became the largest country in the world by area. Comprising more than half the North American continent, Canada stretches from the Arctic circle south to the 42nd parallel. This immense land mass covers 5 time zones and more than 9.9 million square kilometers. Yet in spite of its vast geographic size, Canada has a relatively small population of approximately 27 million citizens. Of this population, approximately 85% is distributed across a relatively narrow band approximately 350 kilometers wide and 4300 kilometers from East to West. This band stretches along the southern border of the country which it shares with the United States.

Canada is composed of ten provinces confederated in a political and economic union, and two territories governed under the authority of the central federal government. The interdependent and overlapping jurisdictions (economic, social, and cultural) of the federal and provincial governments which currently exists has arisen not only out of the geographic diversity of the country, but also out of its historical evolution. This historical foundation reflects not only the origins of its major cultural groups (Aboriginal, English and French), but also progressive settlement and economic diversification trends within the country.

Specifically, at the time of Confederation (1867) approximately 50% of Canada's workforce was principally involved in primary industry (i.e. extraction of natural resources, eg. agriculture, fishing, forestry, mining, drilling, etc.). By 1989 this had dropped to 5.7% with the largest employment sector consisting of tertiary industry (i.e. distribution of goods or provision of services, eg. finance, insurance, transportation, communication, personal) which employed nearly 71.1% of the total workforce (Brooks & Stritch, 1991). Hence, given the tremendous geographic and climatic diversity of the country, economic, demographic, and to some extent social heterogeneity has been the hallmark of the Canadian context.

Demographic structure

Like most western industrialized countries, Canada faces an increasingly

older population over the next quarter century. In 1983 approximately 10% of the total population was age 65 or older (National Council of Welfare, 1983). In 1986 the median age of the entire population was approximately 31 (Statistics Canada, 1986 Census). This varied from a low of slightly less than 28 years in the most easterly province of Newfoundland to a high of slightly more than 33 years in the most westerly province of British Columbia. In another province (Alberta) 8.1% of its population was age 65 or older in 1986. This latter percentage is projected to rise to 14% by the year 2016 (Alberta Bureau of Statistics). This increase may be partially attributable to a relatively low birth rate as well as an increase in average life expectancy. Again in Alberta, in 1981 the average life expectancy for men was 72.4 years while for women it was at 78.6 years (Alberta Bureau of Statistics). This differential for men and women is expected to continue to the extent that, with increasing age, this older population is expected to be disproportionately composed of women. Indeed, 1981 statistics revealed that 59% of Canadians age 65 and over, and 63% age 75 and over, were women (Heiple, 1981).

While comprehensive data are not available from across the country on the prevalence of developmental disability and its distribution across the lifespan, best available estimates for Canada suggest that prevalence rates for mental retardation increase with age from a rate of about 1.5 per thousand at birth to approximately 4 per thousand after the age of 40 (Baird & Sadnovick, 1985). Similarly, while life expectancy data for individuals with developmental disabilities are unavailable on a country-wide basis, a sample of 742 individuals over the age of 45 in the province of Alberta (Badry, *et. al* 1986) revealed an average age of 60 years for individuals from a cross-section of community and institution-based environments. Of notable significance in the provision of services to persons with a developmental disability, is the relative disparity between urban and rural groups in the availability of and access to appropriate support services. Specifically, individuals residing in more remote locales have minimal resources available to them other than those provided by their immediate families. More specialized services and supports are typically accessible only if individuals move from their indigenous environment to a centralized, typically urban, setting. Coincidentally, for a majority of Canadians this rural-urban distinction reflects an aboriginal-non-aboriginal distinction of the populace.

General Background to Welfare Services

Constitutional authority to legislate in the areas of major health care, social assistance, and post-secondary education (among other things) is the primary prerogative of the provinces. However, cost-sharing and financial transfer agreements between the federal and provincial governments effectively make for joint responsibility in these areas. This joint responsibility is reflected in fairly uniform - although not identical - policies and service systems across the provinces

and territories. As one example of this, in an effort to ensure that the incomes of all elderly people in Canada are sufficient to permit them to "live in dignity no matter what their circumstances were during their working years", and to "maintain a reasonable relationship between income before and after retirement so that old age does not bring a drastic reduction in a person's standard of living" (National Council of Welfare, 1989), the federal, provincial and territorial governments collaborate on the provision of income support programs. In addition, with universal health care access guaranteed to all citizens by virtue of federal cost sharing with the provinces at the rate of 50%, a uniform pattern of care emerges nationally. Nonetheless, the precise structure of social and health services varies across provinces and even across communities within provinces.

General Information on Services to Persons with Developmental Disability

Services and supports to persons with developmental disabilities lie within provincial jurisdiction and responsibility. To this extent, there is no statutory requirement that any province or territory provide a given level of assistance in this area. Generally speaking, however, in keeping with a caring social conscience shared by most Canadians, all provinces maintain relatively vigorous support for services for persons with developmental disabilities. This is reflected in active efforts to deinstitutionalize services, to integrate persons with disabilities into community settings, to promote affirmative action in employment situations, to effect direct consumer (client) participation in decision making. And furthermore, the apparent homogeneity of effort amongst the provinces arises in part from the "levelling" effect that arises by virtue of the conditions placed on the provinces for them to benefit from cost sharing arrangements with the federal government. A second source of harmonizing influence arises from the various groups such as the Canadian Association for Community Living (CACL) and its various provincial affiliates which promote specific ideological and advocacy initiatives to effect change in service provision throughout the country.

In spite of the commonalities in efforts amongst the provinces, they do differ in the extent to which the full array of services and supports are available. In part, these differences may be attributable to the willingness and ability (financially) of each respective provincial government to provide service alternatives.

The array of services for adults, including those for older persons, can perhaps be best characterized as encompassing a continuum from segregated institutional services to individualized support for persons who are fully integrated into their community - residentially, economically, and socially. At the most extreme level of institutional service, individuals receive all of their services (residential, health care, educational, occupational, leisure, etc.) from a single self-contained structural environment that functions somewhat autonomously from its

surrounding community. At a less extreme level, a wide variety of facility-based services situated in the individual's natural community provide the majority of services to Canadians with a developmental disability. These community-based facilities typically include group homes where a small number of individuals (usually no more than six) reside, and workshops where any number of individuals congregate on a daily basis to receive employment and employment-related training and support. These community-based facilities may include "outreach" components which support the individual in making relevant transitions to other types of involvements in the community. These involvements may include semi-independent living, supported employment. Finally, at the most extreme level of individualized support, clients not only have their unique needs met away from pre-established services and facilities, but also have relative control over the utilization of funds assigned to them to purchase the particular configuration of services and supports which best matches their current circumstances. This latter model, although relatively new among most provincial governments is becoming more widely adopted.

Not included in any of the above alternatives are the situations where individuals are not receiving any "formal" type of service but instead are being supported by their natural informal networks (ie. families, neighbors) in their natural environments. The extent to which this occurs is unknown, and in this regard individuals so involved can be considered a hidden population. It is expected, however, that this situation prevails to a greater extent in the non-urban environments mentioned earlier in the paper, and also in situations where the parent(s) of the person with a developmental disability are themselves of considerable age.

A final comment which needs to be made with respect to the provision of services and supports is that in virtually all provinces the institutional models are typically operated by the provincial governments themselves. The community-based and more individualized support models tend to be operated by a variety of voluntary and private organizations, on either a for-profit or not-for-profit basis. In each case, however, the organizations typically receive the majority of their operating funds from the provincial governments. These voluntary and private organizations have proliferated over the last decade as most provincial governments have moved toward privatization of social services.

Services to Older Persons

There is growing recognition amongst most professionals in the rehabilitation field in Canada that older persons with developmental disabilities are comprising an ever larger proportion of the total population receiving adult level supports and services. However, this increased awareness remains at a fairly basic level, with

only a relatively small number of professionals actively engaged in the direct provision of services or in the development of appropriate policies and systems to best meet the current and future needs of these individuals. In relatively isolated cases throughout the country a variety of initiatives have been taken to either meet current needs or to anticipate future requirements. Some of the current programs and supports are summarized below, but before turning to them it should be pointed out that one of the few current initiatives to accommodate future requirements for professionally trained staff is a course in aging and developmental disabilities, offered through the University of Calgary. Also of note is a two-year demonstration project, "Project Inclusion", currently being carried out by the Association for Community Living - Manitoba (Dozar, 1991). This project is endeavoring to develop professional expertise through direct client support in a small number of communities in the province. The approach being utilized is the development of generic age-integrated approaches and client empowerment support to assist individuals with developmental disabilities to select desired alternatives.

At the time of writing, this author is not aware of any explicit policies which have been established by either the federal or any of the provincial governments with respect to the provision of services to older persons with a developmental disability. Nonetheless, independent of any explicit policies or guidelines, what appears to be emerging is an emphasis on integrating individuals directly into the generic seniors systems and networks, particularly in the various community-based cases where direct services and supports are being provided by local organizations. This trend is clearly consistent with the general notion, noted earlier, of full community integration for all individuals with a developmental disability regardless of age.

Examples of current service systems include those in the Niagara region of southern Ontario where a regional body has developed a highly coordinated process for the identification, evaluation and referral of individuals to a network of service and support alternatives for all seniors (Neufeldt, 1992). The services themselves cover the full range from formal to informal support, including: (a) highly structured, congregate living arrangements such as nursing homes; (b) in-home assistance for individuals residing in their own homes; (c) out-of-home assistance to enable individuals to fulfil essential community tasks such as shopping, banking, etc.; (d) support to facilitate the inclusion of individuals in normative seniors activities and social events. These services and supports are available to all individuals meeting requisite age criteria, regardless of any disabling conditions which they may have. Therefore, within this system developmental disability is essentially transparent and presents neither a greater nor lesser criterion for consideration for support and service than any other condition or circumstance which may be associated with increased age.

Another example of a community-based program, albeit designed specifi-

cally to meet the needs of elderly individuals with a mental handicap, is that provided by the Maitland B. Steinkopf Residence in Winnipeg, Manitoba. The Outreach Program of this organization has adopted a highly client-centered approach which is "attuned to their unique and varied needs" (Michaud, 1991). Specifically, the program, which has been in operation since 1988, has targeted those individuals who could be categorized as either the "hidden" population (ie. at home with no services or supports), those for whom existing day services are deemed inadequate, or those who are at risk of being placed in more restrictive environments. For all individuals the aim of the program is to "develop day activities and social networks". This is realized through the provision of referral and support to such resources as vocational, recreational, medical, economic, housing, educational, and respite services, as well as referral to other specialized services.

A more focused approach concerned primarily with the day-time involvements of older people who have developmental disabilities is that taken by Community Living (Owen Sound District in Ontario). Receiving particular attention are individuals who have "retired from sheltered workshops or regular employment, and are reducing their work hours and are preparing to retire" (Hilts, 1991). With the main goal being community integration, individual's interests are ascertained, support then being given to realize and maintain those interests in community settings. Current involvements include library use, trips, weekly luncheons, films, retirement club participation, and bowling.

Another focused program, the Mary Center of the Archdiocese of Toronto in Ontario, provides residential support to individuals fifty years and older and developmentally disabled. Individuals are supported in small group living arrangements (four individuals in one residence) with additional emphasis being placed on integrating them into a variety of community services including generic senior programs (Lomax, 1990).

Yet another focused program for elderly individuals with developmental disabilities is operated by the major institutional facility in the province of Alberta. Specifically, in addition to the major institutional environment itself which maintains a large number of individuals over the age of 45, the institutional structure also operates a number of group homes located principally on the periphery of institution grounds. In a small number of these homes up to 6 elderly individuals reside in an environment that places minimal expectations on them to take independent responsibility for their day to day maintenance.

While the foregoing undoubtedly do not represent the full complement of services and supports to elderly individuals with a developmental disability in Canada, they do represent the range of alternatives which currently exist. With the ongoing development of a network of interested individuals and organizations, a more complete summary of initiatives can be documented.

Current Problems and Future Service Developments

If the demographic data arising from the Badry *et al.* (1986) study is in any way indicative of the overall situation in Canada for older persons with a developmental disability, then the most significant concern to be expressed on their behalf is that for the majority of individuals there is a decided lack of appropriate services and supports for them. They are indeed a population in dual jeopardy - older and developmentally disabled.

Although selected initiatives are currently underway to develop and provide appropriate supports, the general lack of enabling policy and funding will preclude significant development of alternatives in the near future. Many individuals currently residing in the general community will come to receive only a modicum of support only when they move into a crisis situation such as infirmity or death of their parent. Others, without the advantage of either proactive planning or natural transitions to age- and capacity-relevant alternatives will remain within their current infrastructure of services as they age. Only gradually will these existing adult services themselves change as they come to be populated by a "residual" population increasing in age and changing in needs and expectations.

However, on the more optimistic side, as the number of professionals and supporting agencies increases, there is already a corresponding recognition of the need to deal with the emergent issues that this population presents. Some of the initiatives enumerated earlier will provide the base from which relevant service designs and strategies can be developed, and supporting funding and policy provided. Clearly, as the life span of individuals with developmental disabilities increases, both service providers and funders will have no alternative but to respond with appropriate initiatives. Given the general social climate in Canada that exists today, it is the opinion of this writer that the initiatives which are developed will reflect the prevailing philosophy of full integration and community participation.

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CHAPTER FOUR
A German Perspective

by Gottfried Adam

National Background

Today's Federal Republic of Germany is the result of the unification on October 3rd, 1990 of the former West-German "Federal Republic of Germany" (FRG) with 63.5 million persons and the East-German "German Democratic Republic" (GDR) with 16.1 million persons.

Population and Size of Country

The state has now a total population of 79.6 million people in an area of 356,945 square kilometers. Germany is one of the most densely populated areas of the world, with an average of 223 persons per square kilometer, rising to 3,859 in Berlin and 502 in Northrhein-Westfalia.

Former East-German Democratic Republic

The situation of persons with developmental disabilities in the former East-German Democratic Republic was very difficult. According to the Communist ideology, persons with a mental handicap did not exist in a Socialist society; such a handicap could only be the result of the Capitalist system. As a result, the state gladly abdicated responsibility for these individuals in favor of the Church, who cared for them in homes and institutions. The Church authorities were not, however, allowed to give them a formal schooling, because the law stated that trainable mentally handicapped children and youth were not entitled to attend school. There is insufficient information available to draw a clear picture of the situation in the former GDR. It would in any case be only of historical interest, since the situation is changing so profoundly.

Following reunification, the whole structure of social services in the eastern parts of Germany (former GDR) has been brought into line with the regulations and standards of the west-German Federal Republic. In the following article I shall, therefore, refer only to the situation in West-Germany.

Age Structure of the General Population

Life expectancy in Germany is high: 72.2 years for males and 78.7 years for females (April 1991). This represents an increase of about five years compared to the situation ten years ago. The life expectancy of developmentally disabled persons has also been growing during the last two decades, and today is almost as great as that of the general public (Huber 1990, 223). This implies a growing need for services for the older members of this group.

As with other developed countries, Germany's population is "greying". Indeed this trend is so marked that the death rate has continuously outstripped the birthrate since 1971. It is the fact that people from other countries immigrate to Germany which leads to a positive demographic statistic.

General Background and Structure of Welfare Services

Thanks to Germany's strong economic foundation the funding of the social system has been steadily growing and expanding over the years. Of course, there are always areas where more funds are needed. In terms of world comparisons, however, Germany's social services are based on one of the surest financial footings with a firmly established principle of universal availability. In the German social system, however, the main funds come not from private sources or foundations, but from public tax-money. However, the principle of *Subsidiarität* is basic. By *Subsidiarität* is meant that any free, non-state institution or agency can engage in social issues and establish social services. In other words, where there is an appropriate voluntary organization to take over a task, the state is required to fund the voluntary organization to provide the services rather than providing the service itself. Where there is no appropriate organization the state itself becomes the service provider. In either case, the distribution of the funds is handled by the government's social welfare institutions.

Since there is a legal basis for the establishing of a wide variety of social services, most of the money comes on a statutory basis. This applies whether it is used to fund a state institution, a church agency or some other private organization.

General Information on Services to Persons with Developmental Disability

Service Providers

Because of this *Subsidiarität*-principle a large percentage of services provided are provided by parents' associations, the Protestant and Catholic churches and other private organizations. Especially active in our field of concern are the

Diakonische Werk (Protestant Church) and Caritas (Roman Catholic Church) and (the parents' association) *Lebenshilfe*.

Type of Services

Residential

Germany has a strong tradition of institutional care for persons with mental handicap. The churches started to care for this group of persons at a time when nobody else was thinking and caring about them. In the old large institutions there was always room for handicapped persons of all ages.

The national policy regarding service provision favors integration into community, although this trend toward "normalization" is stronger in the northern states of Germany than in the southern states. In relation to children with developmental disabilities, new service institutions have been developed to provide (a) early stimulation, (b) special needs schooling in the community and (c) sheltered workshops. Regarding the closing down of institutions, there is not such a strong movement as in some other countries (e.g. Sweden, the USA and Great Britain). However, what is happening in some institutions is that living arrangements are becoming more flexible. In some instances, living arrangements for developmentally disabled persons and staff are completely mixed (cf. Bethel). In other cases, big institutions rent or buy houses or apartments in the living areas of cities or towns, and have developmentally disabled persons living in small group homes. This gives the opportunity for the persons to return back to the bigger institutions when the changing needs or the inability to continue living in such an independent arrangement require this. This flexible system of a regional network tends to be a widely accepted philosophy.

Day Services

The guidelines which are set up by the State authorities for sheltered workshops focus on industrial work. The official aims do not include social, educational or leisure pursuits. As a result, any initiatives in these directions depend solely on the efforts of individual workshop personnel. Sometimes, for instance, there is a small workshop division where items such as paintings, woven articles, arts and crafts, and other creative things are produced.

The specified economic aim to produce a certain level of output creates a dilemma, in that workshop staff have little time to provide activities relating to personal development and leisure. The following two examples, however, show creative solutions to this problem: (1) In Wurzburg the problem is being solved through cooperation with the local adult education institution (*Volkshochschule*); courses are offered that take place during work time and in the rooms of the workshop. In addition, University students offer leisure time activities for two

hours on a Friday afternoon when the work period is over. (2) In Hephata, a town in Hesse, the workshop is closed on Wednesday afternoon. This time is used for excursions, e.g. going to a coffee shop in town, going shopping and learning to handle money.

Services to Older Persons

Level of Awareness

Since the end of the sixties, there has been a growing awareness for the needs of handicapped persons and a tremendous development of all services. In the seventies especially, one saw an "explosion" of new service provision, the work and pressure of parents' associations having had a big impact on this development. Nowadays developments move ahead more slowly especially since funds are more difficult to get.

In German society the awareness of the needs of a variety of specific handicapped groups is currently growing. About ten years ago the question of older and elderly developmentally disabled people became increasingly pressing. There were now people who had gone through school, lived and worked in a variety of day and residential settings, and were now reaching retirement age. This focus is being reflected in the increasing awareness, especially amongst parents' associations and church agencies, of the needs of their older clients.

The Growing Number of Older Persons

At the moment there are no exact data available on the number of older and elderly handicapped people. Haack (1989) has given us a picture from the regional area of Wilhelmshaven in the northern part of Germany, which undoubtedly reflects the general tendency. The following statistics show how the age structure in a sheltered workshop and the connected residential homes is projected to change from 1980 until 1998.

Age	1980	1988	1998
15 - 29	58.3%	39.5%	15.7%
30 - 49	23.4%	40.9%	54.2%
50 - 64	12.6%	16.5%	25.8%
over 60	5.7%	3.1%	4.3%

It can be seen that there is an increasing proportion of people over 30 years of age, with a corresponding reduction of people under 30. The rising proportion of people in their 50s and 60s implies a need for changing concepts of activities, a growing demand for activities appropriate to older individuals. This situation can only be handled properly within a coordinated system of differentiated services in residential and day service provision.

Retirement Policy

Persons with developmental disabilities retire at the age of 65 as do all other persons in Germany. If their health is declining they can go at an earlier age. Until recently, there has been hardly anybody attending workshops older than 50 years. This is because the vast majority of older people with developmental disabilities were living in large institutions until the founding of the Bundesvereinigung Lebenshilfe. Although there is a statutory retirement policy, this policy is interpreted flexibly to take account of the specific needs of individuals.

For example: (1) Gradual transition to retirement: in Wurzburg, one woman attends the workshop for a reduced number of hours during the day, and is looked after for the rest of the day in her group home. (2) Working beyond the statutory retirement age: in the rural area adjacent to Wurzburg, two people who are older than 65 still go to their workshop, because there is currently no possibility of looking after them in the residential home. They are both able and willing to continue in the workshop.

Involvement of Families

Regarding the family support systems there are again no exact data available about the proportion of older developmentally disabled persons that are being cared for by their ageing parents. However, Huber (1990) and Beermann & Reischuck (1987) estimate that about half of the adult trainable mentally handicapped persons are living either with their original family or with close relatives.

Parents are involved in decision-making about services, especially through the parents' association *Bundesvereinigung Lebenshilfe*. The different organizations that are engaged in this field consult each other and take an active part in the modelling of the relevant social politics. Since according to our laws everybody is entitled to certain services there are probably few people not known to service providers whether living at home, in a residential facility, or in an institution.

Examples

As the following examples show, service providers are aware of providing for older developmentally disabled people a life situation that is adequate to their age and situation. They get the opportunity to do something for other persons, and enjoy integrated experiences such as senior citizens' clubs.

In a residence of 40 persons, run by Lebenshilfe in Wilhelmshaven, 20 older and elderly handicapped persons are living. They can stay there all day long, the necessary staff being paid for by social welfare. This group of people have a special

room to take it easy, they are being offered a regular and permanent training to keep them fit and mobile, and they are under medical supervision. They are trained to take care of their own rooms, to participate in the kitchen work, look after flowers and take care of vegetable beds. The general aim is to provide them with appropriate meaningful activities, and the experience in this facility has demonstrated the continuing ability of mentally retarded persons to learn new skills, even in old age (Hoß, 1988).

In the Elisabethenberg, a part of the church institution of Stetten in Baden-Wurttemberg, a club for seniors is being offered. The clients can go to the meeting point whenever they want. There is a nice room with a big round table in the middle, another big long table, a sofa for resting, and a small kitchen. The club is open between 8.30 and 11.00 a.m. and from 1.15 until 4.00 p.m. The program consists of a mixture of individual activities (knitting, talking with each other, rest, play puzzles, etc.) and group activities (games, songs, tea or coffee break, etc.). The day is structured such that individual activities take place first with communal activities taking place shortly before midday or in the afternoon. If the weather is sunny, walks and excursions by bus are offered.

Current Problems and Future Service Developments

Current Problems

During the coming years we will have to cope with a rapidly growing number of older and elderly handicapped people, especially when the "boom" cohorts are getting older. This increasing proportion of elderly people in the general population will be matched by a similar change in the age structure of the severely and profoundly disabled population, making it necessary to build new residential facilities. There are two possible solutions: (a) building special homes or (b) integrating the persons in homes for the general elderly. From the principle of normalization the latter would seem a more appropriate alternative. However, a question receiving very serious attention is whether it is not necessary to build special homes to cater for the special needs of this group of persons. As with the general elderly population, older people with developmental disability are not a homogeneous group. To meet these diverse needs the first principle thus has to be flexibility. A good service system should take into account the special needs and special situation of each individual person.

There is a necessity to get more exact data for the planning of the needed service system. Already, however, one of the problems that can be foreseen is that there will be a lack of persons who are willing to go into this kind of work. We currently have a shortage of staff in this field, and this problem will increase since the present "mood" in German society is not directed towards social issues and professions, but rather to economic and commercial success. Young people prefer

studying and working in the fields of economics and sciences.

Future Developments

Future developments will hopefully bring about an expansion of the range of services available. For example, the new tendency in generic elderly services, to pay families for the care of their older relatives to prevent institutionalization, is promising. However, it is doubtful whether this will have any impact on the situation of older and elderly people with developmental disabilities. Taking care of them in old age might be too difficult a task for the regular family because of the increasing risk of age-related conditions necessitating nursing and medical care. At the moment there is a tendency to place persons with the most severe handicap in institutions.

A service system able to cope flexibly with the needs of older clients demands a coordinated network of residential facilities offering the following choices: (a) own family home, (b) alternative family, (c) single units with ambulatory care, (d) group units with ambulatory care, (e) group units with intensive care, (f) in residential homes (with around 16 people) with intensive care, (g) institutions, old people's homes, geriatric care centers, (h) hospitals. (Hentschel & Wilke, 1990, 37 f).

While the provision of these facilities represents a major challenge, we must not lose sight of an equally important task, the maintenance of a quality of life in whatever situation the individual is living. Here, we need an improvement and expansion of day care services in residential facilities and in communities in order to maintain and enhance self care and community living skills, a goal which is essential not just for developmentally disabled individuals but for many members of our aging population. To achieve this aim we need: (a) lively activities to maintain physical and mental alertness, (b) a stimulating environment, (c) social contacts with friends, (d) opportunities to deal with religious questions and practice, (e) the choice of different activities, (f) physical and medical health care. Some people have suggested that we need to develop new professions to meet these demands (cf. Bartel, 1990).

However we achieve these goals, the ultimate aim should be to help our older developmentally disabled people spend their later years in as normal and fulfilled a way as possible.

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CHAPTER FIVE
A Perspective From Hong Kong

by John W.L. Tse

Introduction

In 1990, the total population of Hong Kong was 5.9 million, comprising three million males and 2.9 million females. Over 95% of the population is Chinese by origin. With a total area of only 1,075 square kilometers, Hong Kong is one of the most densely populated places in the world, with an average population density of 5,430 per square kilometer (Hong Kong Government, 1991a). Table 1 shows the life expectancy of the general population which is rising and is projected to continue to rise.

In the last 10 years the proportion of people aged 60 and above has risen from 10.2% to 13.3%. In Hong Kong, there is a lack of concrete figures on the life expectancy of older people with developmental disabilities. However, it is a reasonable assumption that improvements in medical and social conditions have raised the life expectancy of people with learning disability, as in other countries. In Hong Kong a prevalence rate of 2% was adopted for estimating the number of people with mental handicaps: in 1990 the total number was 113,667. From these figures, the projected rate of people with mental handicaps aged 60 and above would be 14,775 (Government Secretariat, 1991).

TABLE 1
Life Expectancy of General Population

(Report of the Central Committee on Services for the Elderly, 1988)

Year	Male	Female
1971	67.8	75.3
1981	72.3	76.2
1991 •	75.1	80.9
2001 •	76.7	82.4

• projected

Background to Welfare Services

The Social Welfare Department and voluntary agencies work in close partnership in providing welfare services. Some of the responsibilities of the Social Welfare Department include providing social security, statutory services and direct services. There are a total of 160 voluntary organizations which operate over 1500 service units and 60 types of services. The source of such funding is largely subsidized by government. Voluntary agencies employ about 80% of all social welfare personnel and are responsible for spending about two-thirds of the expenditure on social welfare services (WPSWPS, 1990).

In the past ten years, public expenditure in welfare services has risen from about one billion dollars (equivalent to 77 million pounds or US$ 128 million) in 1981 to approximately five billion dollars (equivalent to 386 million pounds or US$ 641 million) in 1991. The latter represents about five% of the total public sector expenditure (WPSWPS, 1990).

Services to Persons with Mental Handicaps

Most Western countries have long adopted the policy of deinstitutionalization. In Hong Kong, the deinstitutionalization movement has been less in evidence, due mainly to the fact that residential provision has historically not been based on large institutions. Currently, the largest facility is for persons with severe retardation, accommodating 200 adults. As a result of this difference, there are fewer apparent barriers to the implementation of a normalization policy than in some countries. However, its application in the Oriental cultures may pose some difficulties (Stratford and Tse, 1989). In the West, adults especially those who are self-supporting are expected to live independently, away from home. This may also apply to persons with mental handicaps, hence the setting up of community-based group homes. A similar situation, however, does not automatically apply to Chinese families in Hong Kong. Even though increasingly more adults do not live with their parents, most young people before they get married are expected to live with the parents. In Hong Kong, persons with mental handicaps with very limited income, do not have the means to live independently and are expected to live with the family. Given the limited housing space in most families (the average gross floor area per person is 7.0 square meters or 70 square feet), the presence of a person with moderate/severe mental handicaps may pose excessive stress and burden to the family. Though results of a formal research is not available, many parents have expressed informally preference of institutions over community-based facilities for their son/daughter.

While there has been no formal policy declaration on deinstitutionalization and normalization, the objective of service provision was spelled out clearly in a government policy paper in 1977:

"To provide such comprehensive rehabilitation services as are necessary to enable disabled persons to develop their physical, mental and social capabilities to the fullest extent which their disabilities permit" (Hong Kong Government, 1977).

Despite the fact that the title of the paper was on "integration", there had at that time been little advance in the integration of persons with mental handicap into community life,eg. by living in ordinary housing, or participating in ordinary community activities. In the last ten years, there has been much expansion in the setting up of hostels and sheltered workshops for adults with mental handicap. Hostels mainly provide dormitory type of accommodation for as many as 50 adults. However, there are still very few community-based homes which resemble family-like type of accommodation.

In 1989 the Social Welfare Department adopted a five-level model of accommodation for adults with mental handicaps (Hong Kong Government, 1991b).

The levels are as follows:

Level 1:

Supported Independent Living (Flats for persons who can live independently)

Level 2:

Supported Housing (Eight 3-person units in public housing estates, with limited supervision)

Level 3:

Supported Hostel (Small group home of 20 places in public housing estates, with the support of a small team of six staff)

Level 4:

Hostel for People with Moderate Mental Handicap (Unit to house not more than 50 with a team of 15 staff)

Level 5:

Hostel for People with Moderate/Severe/Multiply Handicapped. Persons (Unit to house not more than 50 persons who lack basic self-care skills and require intensive care training, with a team of 29 staff)

Though the five-level model is more in line with the trend of normalization and community-based residential services its implementation, apart from level 4 and 5, has been exceedingly slow. The shortfall of hostel places for adults with moderate mental handicaps and severe mental handicaps is 47% and 73% respectively (Government Secretariat, 1991). Residential services for adults with mental handicaps are mostly provided by the Social Welfare Department and voluntary organizations; there is only one privately run residential unit in Hong Kong.

Day Activity Centers (DACs) provide day care and work activity training to adults with mental handicaps. The purpose is to help them to become more independent in their daily living and better prepare them for work in sheltered or supported employment. This transition, however, can only be described as infrequent. DACs cater mainly for adults with severe mental handicaps, but currently have a 60% shortfall in the number of places available.

The severe shortage of residential services literally means that one may have to wait for years. In the light of this, the Social Welfare Department together with some voluntary organizations established home- based training programs in 1987. Training is provided by home-visiting teams, with the participation of the family members. A total of four teams were in operation, serving about 300 adults and their families. The program was meant to be transitional and would enable some level of training at home while awaiting placement (Crawford and Tse, 1989). Despite these efforts, it had been estimated about 40% of school- leavers with mental handicaps received no further services after schooling (Hong Kong Association for the Mentally Handicapped, 1988).

Services to Older Adults with Mental Handicaps

Traditionally, the field of mental handicap has been one whose focus has been primarily upon children, and secondarily upon adolescents and adults. It was not until the 1970s that adults with mental handicap became the focus of a substantial amount of concern. With the "graying" of the mentally handicapped population, more recognition is now being given to those adults with mental handicaps who are aging. The need for age- appropriate services for adults with mental handicaps is now commonly recognized by service providers. In general, however, most policy makers and even some service providers remain "backward" in terms of their level of awareness of needs and problems of older adults with mental handicaps. Policy makers are ill prepared to cope with the emergent problem of aging and mental retardation. The service needs were recognized only recently in the Hong Kong Rehabilitation Program Plan Review, 1987, which presented the existing provisions and planning of rehabilitation services in Hong Kong.

Many countries are now trying to find ways to establish an appropriate continuum of care services throughout the life span. Hong Kong has yet to make policy decisions in this area. The centerpiece of these decisions is the day activity center and sheltered workshops for adults. Should these individuals eventually retire from these programs? This question was not asked until recently. Apparently, there is no stated policy to deal with the problem other than a "wait-and-see" attitude. Services such as group homes, recreation programs, day programs and residential services, which are needed for older adults with mental handicaps, are often lacking.

Due to the lack of central policy, some older adults with developmental disability were referred to receive residential services in privately run hostels or homes for the general elderly population. This raises a number of further issues. Should these older adults be regularly referred to "care and attention" homes on the same as-needed basis as the general population? Are these institutions ready to accept them?

Recent plans have included the provision of "care and attention" services for older adults with mental handicaps who have very low functioning level, chronic mental and/or physical conditions who require intensive personal care and constant nursing care. It has been estimated that about 400 persons with mental handicaps aged 40 and over may require this service (Government Secretariat, 1991). The setting up and running of such residential services is the responsibility of the relevant government departments and voluntary agencies. For instance, a voluntary agency has recently established a residential unit to provide accommodation for 20 older adults with severe mental handicaps.

A recent survey located nine adults over 55 years old with developmental disabilities (Hong Kong Council of Social Service, 1988). In terms of residential services, four stayed in a large psychiatric hospital, one stayed in a hostel and two stayed in care and attention homes for the elderly. Two received day programs in a social recreation club. The findings may give a general picture of the life-styles of these people which could best be described as "institutional". Those who stayed in a mental hospital lived in wards with a minimum of 90 beds. They did not have any personal belongings and rarely participated in social events or were visited by any relatives. Though elderly homes in general are less regimental than that of psychiatric hospitals, the quality of life of the residents is low. The environment is devoid of stimulation and the individuals are mostly left idle throughout the day in a common room typically furnished with a television set and very plain, long lasting furniture. Life-style is restrictive and the common atmosphere is dull.

Retirement planning, which is already grossly inadequate in the general population, is particularly lacking in the retarded population while there is an additional hardship faced by non-working members of the population. Hong Kong has a non-contributory social security system, under which older adults with mental handicaps are eligible for a disability allowance of $745 (£57 or US $96) and a monthly supplement of $343 (£26 or US $44) per month. (Hong Kong Government, 1991b). With such "income" one can only afford to live at a below subsistence level.

Current Problems and Future Service Developments

Although the projected number of persons with developmental disability in

Hong Kong in 1990 was over 110,000, the record in the Central Registry for the Disabled indicated there were only 16,000. Out of this figure, only 174 adults over 55 years of age were identified. Where have all the older adults gone? These people could, in varying degrees, be described as a "hidden population". In the past, medical practitioners used to classify "mental deficiency" often without the aids of standardized intellectual assessment tools. Such practice might enable one to identify, accurately or inaccurately, individuals with severe mental handicap. The ability to differentiate individuals with mild mental retardation diminished and was at best questionable. It is, therefore, likely that a vast majority of this population has not been identified. Given that the general trend of the aging population is similar to other developed countries, there is no reason to believe that there is a significantly lower prevalence of older adults with developmental disability than in other countries. This suggests there is a huge potential client group receiving none of the specialist services to which they are entitled. In future, there is an urgent need to develop reliable and valid intellectual assessment tools in order to assess and identify mental retardation in the older population. This, however, raises ethical issues concerning the enforced identification of an unknown population, especially when they apparently are well integrated into the society.

As already mentioned, the shortfall of places in care and attention homes for older adults without handicaps was about 60% in 1991. Competition for resources present us with dilemmas: children's services vs. elderly services and services for children with mental handicaps vs. services for older adults with mental handicaps. These dilemmas are further complicated by the exclusion of parents in the decision-making process and the lack of general support in the community itself for community-based development of services for older adults with mental handicaps.

Conclusion

Undoubtedly, Hong Kong's service development in this area is in its infancy. Recognizing the needs of older developmentally disabled individuals is an important first step. Given the shortfall in provision, the service needs of this population require immediate attention and should be given top priority in terms of resources and support. Policy makers and service providers should be rushing to the drawing boards and begin to develop models of services for the aging and aged people with developmental disability. There is a need to work cooperatively with their counterparts in the aging field to ensure that older adults with mental handicaps can and do access all the services they need and are entitled to (Tse, 1991). The pathway to developing quality services is not without hurdles. Unless the community becomes more positive, unless more staff development opportunities are provided, and unless more resources are allocated into this much needed service, the future is grim.

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CHAPTER SIX
An Indonesian Perspective

by Dharmana Lianta

National Background

Within Indonesia there is currently almost no awareness of the special needs and problems of older mentally retarded persons, either because these people are comparatively rare or not identified. In Indonesia, the extended family is still the predominant social model; it is common to find three or four generations living together under one roof. Awareness of the problems of older people with mental retardation is, however, increasing. This is particularly so in urban areas, where economic pressures are making it more difficult for the younger family members to sustain the older ones. As a result, there is an increasing number of old people's homes appearing. Given the dearth of information, the majority of this chapter focuses on the general provision of services to people with mental retardation.

Indonesia is a country consisting of about 13,367 islands, extending from six degrees northern to 11 degrees southern latitude, and from 95 degrees to 141 degrees eastern longitude. There are about 180 million inhabitants, including unaculturated tribal groups, who live in boats or floating houses and homeless groups.

The geographical spread of the Indonesian population is uneven; about 60% live on the island of Java, although Java's area represents only one-fifteenth of all the islands together. There are many ethnic groups living in Indonesia, including the Javanese in Central and East Java, the Sudanese in West Java, the Dayaks in Kalimantan, the Papuas in Irian Jaya, . Bahasa Indonesian is the national language, although there are 200 other languages as well.

The number of people in Java registered as mentally retarded is 437,074, the number outside Java being 301,223. However, Java possesses the vast majority of facilities for persons with mental retardation, including 90% of the institutions, 87% of the schools for mildly retarded and 77% of the schools for moderately retarded. This imbalance results mainly from the historical development of services. Care for the mentally retarded started at Bandung, West Java, when in 1927 the Folkert School for Mentally Retarded was founded. Also, schools for teachers of special education, schools for speech therapists, and others. began in Java and have continued to develop there until the present day. Life expectancy of the general population of Indonesia is now above 60 years. With respect to the life expectancy of persons with developmental disability no data are currently available, although

it can be assumed that improvements in public health have had a positive impact on all sectors of the population.

Services

Services to developmentally disabled persons in Indonesia face formidable barriers to implementation. These problems include adverse geographical factors, superstitious beliefs, and ignorance about developmental disability. Superstitious beliefs (especially in the rural community) can affect rehabilitation motivation, both on the part of carers and of the disabled persons themselves. Rehabilitation intervention cannot be accepted passively, but requires active input from users and carers.

Traditional beliefs concerning the causes of disability can be particularly problematical, attitudes such as disability being the result of obstruction by invisible spirits, or disability caused by the divine rule of revenge. According to this latter rule, a person becomes disabled as a repayment for bad deeds, or for those of his/her father's or forefather's. Disability is sometimes also regarded as pre-destined by God.

The geographical barriers to service implementation result mainly from the vast number of islands and their physical separation. 84% of the area is sea, the farthest distance from West to East being 5,110 kilometers, and from North to South 1,888 kilometers. In addition, transport is made yet more difficult by the presence of 128 volcanoes, 536 rivers and 27 lakes.

Most of the services for mentally retarded persons in Indonesia are provided by private not-for-profit organizations, both religious and non-religious. These agencies are involved with about 70% of individuals receiving professional support. They run institutions and special schools, which usually receive aid from relevant government departments such as the Departments of Health, Education, Social Services, and Labor.

The specific form of government support varies from department to department. The Department of Health, for instance, gives aid in the form of medical equipment and personnel such as physiotherapists; The Department of Education supplies a number of special education teachers for private schools, as well as equipment; The Department of Social Services provides milk and snacks, and supplies tools for teaching skills like sewing, etc. In January 1989, an agreement was signed between the Department of Labor, Department of Social Services, Department of Internal Affairs and the Association of Indonesian Industrialists. This agreement made arrangements to harness more efficiently the work skills of handicapped people who had already received rehabilitation training.

Figure 1 represents the avenues down which disabled members of the community receive (or do not receive) services.

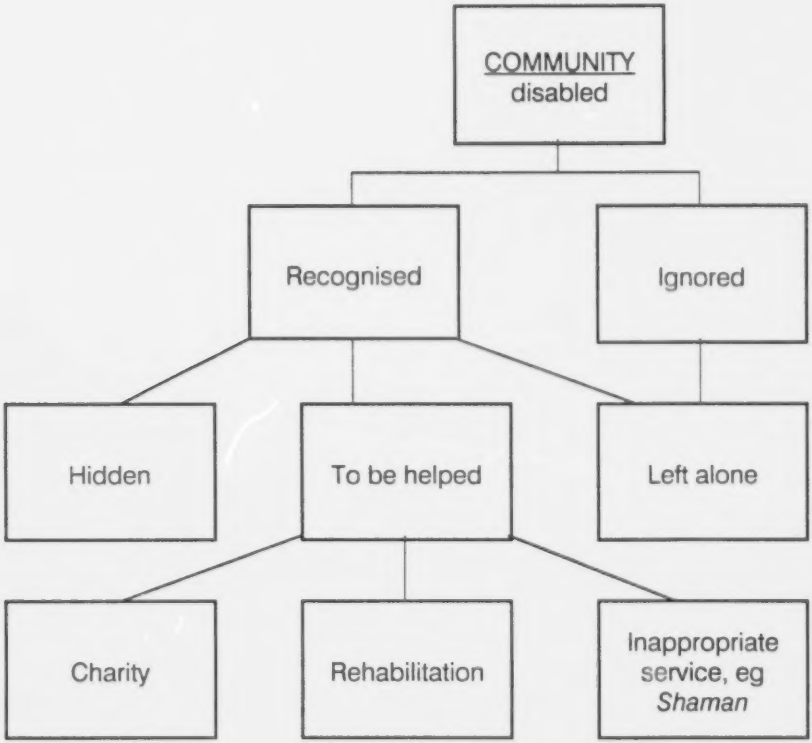

Figure 1.

Apart from the examples given in the paragraph above, all these government departments have specific statutory responsibilities in relation to people with mental retardation. The main functions of the Department of Health include preventative, promotive and rehabilitative work, including the early detection of mental retardation in children under five. The Department of Education develops curricula for special education schools, is involved in the founding of special schools and gives guidance to special schools and their teachers. The Department of Social Services gives guidance in the setting up and development of social

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welfare organizations. In addition, community social workers have a mandate to strengthen social participation as a counterpart to statutory social welfare provision.

Community-based Rehabilitation (CBR) Programs

The CBR initiative began in 1981 and is still continuing to develop. The aim of CBR programs is to provide intervention, training and guidance for individuals in the community who, for the reasons discussed earlier, would not otherwise receive a service. The CBR programs focus on the child within the family context, ensuring that the normal process of child development is preserved as far as possible within the limits of the child's disability. Since traditional beliefs play such a great role in rural areas, CBR programs are closely integrated into this cultural background. The Shaman is the key individual within this cultural context to whom people with a retarded child look for hope and guidance. It is thus very important for the Shaman to be closely involved in the CBR, and to be given information about the cause of disability and how to rehabilitate the individual, e.g. by making regular visits to an appropriate rehabilitation center.

Integration

The national philosophy regarding the provision of services to developmentally disabled persons is that of normalization. This was underlined by President Soeharto in 1981 (launching the International Year of Disabled Persons) where he said "What the disabled persons need is normal treatment, a helping hand and opportunity to work in accordance with their capabilities". Although there are few formal integration programs currently in existence, I know of one foundation with about 1,100 clients with a variety of disabling conditions including sensory impairments, mental handicap, physical handicap, multiple handicap, mental illness and age-related infirmity. There are also orphans. The residents live in 70 houses interspersed in the community.

In an agricultural country like Indonesia, most of the mildly and some of the moderately mentally retarded people can function well within the community context; they can work on rice fields, look for grass and leaves for the goats and cows and plait mats. Integration is thus relatively easy and natural in the rural areas. Integration within urban areas is considerably more difficult; the individuals go to special schools but there is less work available which is appropriate for their developmental level.

Despite the general ease of integration into rural areas, problems do arise when the individual also has behavior problems, or is severely retarded or epileptic. In the case of these individuals, it sometimes happens that the parents keep their child hidden from the public eye because they are ashamed for their clearly visible abnormal child, because of superstitious beliefs which blame the

parents as being the cause of that disorder or because the child is teased by other children. It then becomes the task of community social workers, with the help of village leaders, to try and locate these individuals to provide appropriate support and services.

Compulsory education for all was introduced in Indonesia in 1984. Educational provision for retarded persons includes a number of options: segregated special education, integrated special education, and special classes for handicapped children living in remote rural areas. (These special classes are managed by special schools operating within urban areas).

The following table gives an idea of the numbers of special schools in Indonesia:

	Visually Handicapped	Auditorily Handicapped	Mentally Handicapped	Physically Handicapped
State	12	5	18	6
Private	48	60	145	40
	60	65	163	46

Total: 334 special schools with 21,000 pupils.

An Example of an Older Indonesian With Mental Retardation

Although it has been said that the identification of older persons with mental retardation is difficult, a number of individuals can be found in the growing number of old people's homes. This is an example of one such individual.

Anna, born in 1925, was the fifth daughter of six children from a Dutch family. Having a mild degree of mental retardation, she did not finish elementary school. On leaving school she helped her oldest sister to do jobs like cleaning the house, washing clothes, etc. When the Japanese came to Indonesia during the Second World War, she was "married" to a Japanese soldier, but subsequently became mentally ill and was put in a psychiatric hospital. Eventually, she was placed in an elderly persons' home and has lived there until the present day. Her activities in this home are given as "praying, eating and sleeping". When I asked her why she did not do some other work like gardening, or cleaning her own room, she answered that she had already worked too hard when she was young.

In terms of poverty of service, this is an extreme example. Other institutions have better day programing, including individual and group activities, which may be roughly grouped under expressive arts, craft work, self-help skills and sport. Activities in the realms of expressive art include: dancing, singing, playing music and painting. Craft work includes: sewing, making flowers and other needlework.

Self-help skills include: cooking, ironing and cleaning the room. Sporting activities include: walking, gymnastics and other recreational activities. In addition, individuals are involved in a range of religious activities.

Generally speaking, older people with mental retardation living in old people's homes appear to be well integrated with the other non-retarded residents. The integration of retarded and non-retarded persons does not usually cause any problems, although the retarded members sometimes need a greater level of support, for instance, to take a bath or to eat their meal.

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CHAPTER SEVEN
A Japanese Perspective

by Takeo Kanetsuki

National Background

The territory of Japan consists of four major islands and innumerable small ones. The total territory covers an area of 372,313 square kilometers, with a total population of 123 million as of 1st October 1989.

Japan's population enjoys the greatest longevity of any country in the world, with an average life expectancy of 76 years for men and 82 years for women. Note 1: Health and Welfare White Book of 1991, edited by Ministry of Health and Welfare. Among women and a changing attitude in society towards supporting elderly persons. (It is estimated that there are approximately 600,000 elderly individuals who are either bed-ridden or otherwise handicapped in their ability to conduct the activities of daily life). As with other industrialized countries while the longevity has been increasing. It is expected that Japan will eventually have a quarter of its population over 65 years of age (ICSW, 1990). There is increasing concern on the part of service providers, families and elderly people themselves about the maintenance of a high quality of life in old age. In the past, the proportion of younger to older adults was considerably higher than it is today, with most elderly persons being looked after by their relatives. The ability of families to look after their aging relatives, however, is now diminishing not just because of this changing ratio, but also because of increased opportunities for employment

With this projected dramatic increase in the proportion of elderly people, much of the development of social services in Japan is being directed towards the provision of services designed to increase quality of life in the later years. A number of measures have been adopted to promote and encourage the development of public services in the fields of welfare and medical care to this group. Notably, the Government has adopted a ten year strategy for the promotion of health and welfare among elderly people, providing goals for both community and institutional services. This initiative was set up in 1989.

Much of the effort in providing services to older people is directed towards community provision to enable people to remain in their own homes when their physical abilities are diminishing. There is to be an expansion of programs related to home-help, day care service, short stay service and financial support to enable domestic alterations to be made. These alterations generally relate to the

improvement of access and mobility within the home.

Although the emphasis is on the provision of home care services, the Government is also committed to the establishment of appropriate institutional care for elderly persons who have become unable to continue living at home. These institutions are also expected to function as core centers for the provision of community services.

Precise figures for the current longevity of persons with developmental disability in Japan are unavailable, because relevant research has not been carried out in our country. However, some findings from research conducted by the Japanese Association for the Care and Training of the Mentally Retarded (JACTMR) between 1984 and 1986 bear on this matter.

It had been a common view that persons with developmental disability do not live beyond 50 years at most. We have come to realize that there are many persons with developmental disabilities who survive far beyond this age.

General Background to Welfare Services

Most of the current framework for social provision in Japan dates from the end of the Second World War. However, the roots of social provision in our country go back much farther than this.

As with many countries, social welfare originated through religious organizations. Within Japan, philanthropic work was carried out by the Buddhists as early as the sixth century. The modern concept of welfare provision could probably be said to stem from the Meiji era (1868 - 1912), when assistance schemes for the poor began to be set up. Throughout the first half of this century a variety of social welfare laws were enacted. After the war, Japanese social and economic systems became modeled along western lines. The present Japanese social welfare system is based on legislation prepared around that time.

In the mid 1950s Japan's economy started to grow rapidly. In 1961 legislation covering national health and pensions were enacted, providing universal coverage for all citizens. Specific laws covering the welfare of mentally retarded individuals were passed in 1960.

Organization and Funding of Welfare Systems

Social welfare in Japan is provided mainly by local government and voluntary organizations. At a national level, the Ministry of Health and Welfare is the central administrative body.

There is a high degree of autonomy on the part of local social welfare administration. The national government is concerned mainly with issues of planning, guidance, supervision and subsidizing. The actual operation of welfare services, however, is largely a matter for local government and the voluntary sector.

Funding of social welfare in Japan is largely paid for out of public funds and regulated by national and local government legislation. Generally speaking, the financial basis of the voluntary sector has been weak, and has therefore depended largely on public financial assistance for support.

Up until recently, the Japanese social welfare system has largely been based on public responsibility. In recent years, however, changes in life styles and expectations have made it more difficult for the public system to effectively carry out all the social welfare tasks. A major question now being asked is how to utilize the power of voluntary and private sector organizations within this frame-work.

General Information on Services to Persons with Developmental Disability

Following a national government initiative in 1982, these core welfare provisions for mentally retarded individuals are promoted: (a) prevention of disabilities, and early detection and treatment measures; (b) home-based and community-based welfare services; (c) reform of institutions.

There are two basic types of residential institution in Japan: rehabilitation centers and sheltered work institutions. The former provides protection, guidance and training for people over eighteen years of age. People with severe retardation are found in these institutions. Sheltered work institutions admit people whose level of retardation is less severe, but who are finding difficulty gaining the necessary skills for open employment. These institutions provide vocational training and employment opportunities to help the residents achieve independence.

Apart from residential placement, there is a wide variety of day and residential services available in Japan. Among the residential options available are: (a) group Homes; (b) transitional facilities for people already engaged in employment, encouraging smooth social participation by providing a place to live and guidance for inter-personal relations; (c) welfare Homes, also for persons who are employed but looking for housing due to family circumstances or difficulty of travel - these usually have about ten people per home.

Non-residential day services include: (a) rehabilitation and sheltered work institutions similar to the residential one; (b) welfare factories, established to provide employment for persons who are capable of work but need a more

sheltered environment than open employment; (c) occupational guidance and daily life training programs for individuals living at home.

Services to Older Persons with Developmental Disabilities

Although there is a comprehensive system of welfare provision to the general elderly population in Japan, there has been little reference to the specific needs of older people with mental retardation. (Indeed, there are no Japanese published studies relating to aging and mental retardation appearing in psychological abstracts from 1970 until the present day - Editor). The main reason for this is the nature of society and service provision in Japan compared with other countries. According to reports from Europe and the USA, persons who have lived their lives in institutions benefit from moving to community facilities. Such as an apparent slow down in deterioration due to aging. In Japan, however, the situation is considerably different because residential facilities have always been small, there has been no tradition of giant facilities. The interaction between residents and members of the community has always taken place to a considerable degree. Indeed, our research described below suggests that activities of daily living continue to improve beyond the age of fifty years. This suggests that our service system is having beneficial effects upon the recipients (Editor's (note : This apparent improvement may be due largely to the effect of differential mortality - i.e. the less able and more vulnerable members of the population are dying earlier, leaving a population of relatively high ability and good health)

A concern with the needs of mentally retarded individuals as they grow old led to a number of surveys being conducted by JACTMR on the actual conditions of older clients who were admitted to residential facilities (JACTMR, 1987). The first of these surveys was a cross-sectional study of 3,213 individuals in fifty-nine residential facilities, conducted in 1984. The second survey was a comparison of 1,424 individuals under the age of forty and over forty, living in twenty residential facilities. The third survey was a longitudinal investigation of changes in 599 persons over the age of forty, conducted over a two year period.

Broadly, results indicated that this is a relatively high functioning group of individuals with few health problems. Over the age of sixty, however, notable declines in functioning were observed.

Activities in daily living showed declines in vision, and locomotion, but little change in eating, toileting and dressing. In the domain of communication, development continued after the age of fifty years.

It had been expected that declines in all areas of functioning would be seen. However, this was clearly not the case. It is to be hoped that these continuing improvements in ability reflect the effectiveness of programming which is being

offered within the facilities. It may also be that individuals with mental retardation do not have a clear concept of "growing old" in the sense of having reached a stage in life when one stops learning new things. This relative lack of consciousness of the aging process seems to make these older individuals more receptive to learning than older members of the general population.

Future Developments

Broadly speaking, services to elderly people in Japan attempt as far as possible to counteract the effects of aging. This aim is the same for people with mental retardation. Counter-measures against the aging process involve both psychological and physical aspects. From a psychological perspective, services should aim to help each individual develop a direction in life - something which encourages satisfaction through achievement. The highest goal that a person can live for is the feeling of usefulness, which is the sense that one has made a contribution to and been recognized as valuable by other persons or society as a whole. In order to realize these aims for developmentally disabled persons living in residential settings, it is necessary to: (1) provide a stimulating environment within the residence, reflecting the norms and culture of society at large; (2) maintain daily contact between residents and people outside the facility. (The maintenance of warm human relationships among people within and outside the facility is an important aspect of the support of our aging individuals with mental retardation); (3) establish hobbies and/or tasks to which the residents can devote themselves and whose results can be recognized by others such as painting, pottery, horticulture and farming.

A Life-Span Perspective

To stay young and live longer is the wish of every human being. However, aging starts at the moment of conception. Early detection and early intervention during infancy, education and discipline during childhood, mental and physical training and learning self control during adolescence, work, use of leisure time, and development of hobbies during middle age, are all connected with the prevention of aging. Our services should thus be geared to maintaining stimulation throughout the life cycle.

CHAPTER EIGHT
A Perspective From The Netherlands

by Meindert J. Haveman and Marion A. Maaskant

The Country

The Netherlands is a relatively small and crowded country of 41,574 square kilometers (nearly 15 million inhabitants in 1989) in Western Europe. In the north and west it borders on the North Sea and in the east and south on Germany and Belgium. About 26% of all inhabitants are 19 or younger and 13% of the population are 65 or older. Of the total population 4% are non-native, with Turkish and Moroccan people as the largest groups. In addition, a substantial part of this population consists of inhabitants of the former Dutch colonies such as Surinam (Dutch Guiana) and the Dutch Antilles.

The Privacy of Private Initiative

In many areas of social provision - not only health care, but also social services, education, sport, recreation and the media - the Netherlands citizenry themselves took the initiative in developing services. This so- called private initiative has its roots in the pursuit of emancipation of the two largest religious groups in the Netherlands, the Protestants and the Catholics.

Since the end of the previous century a wide variety of facilities have been set up and managed for and by the separate religious groups in their own societies and foundations. As a result, a system arose consisting of protestant facilities, catholic facilities and an additional third party of facilities, neutral of ideology. There are only few State-owned facilities or facilities owned by the provinces and counties.

In respecting the autonomy of these various welfare agencies, government effectively leaves it up to the private organizations to decide in the manner they will execute tasks in the area of health care and social services. Various efforts to replace this principle of initiative in the organization of health care with a more government-controlled system have met with little success.

Financing

Eventually the resources of the private organizations proved to be insufficient to meet the needs of an increasingly complex welfare system. As a result, the

government started to give financial assistance in the form of subsidies. After the Second World War a financing system of private and social sickness costs insurances was developed to complement the subsidy system. These sickness costs insurances have in effect taken the place of direct government subsidizing of health care.

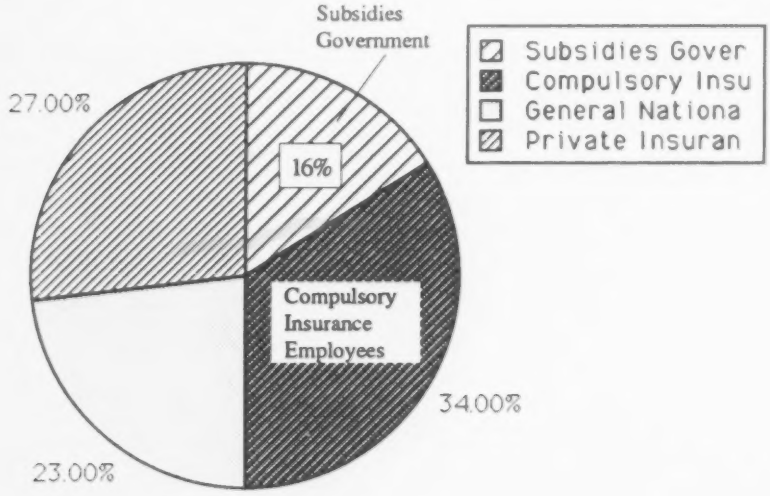


Figure 1: Financing health care in the Netherlands;
1988 = 44 billion Dutch Guilders
1 guilder = 0.54 US $

The social sickness costs insurances consists of two parts:

(a) A compulsory insurance for employees up to a certain wage level above this level one must be privately insured) which covers nearly all individual sickness risks.

(b) A limited general national insurance for all citizens, which covers a few special health risks, in particular the lengthy stay in a hospital, nursing home, psychiatric institution, institutions and group homes for the mentally handicapped.

These two social sickness costs insurances cover only the costs of medical and para-medical aid. The principle underlying the social sickness costs insurance

is "provision in kind" : the insured person pays a compulsory annual premium to a national insurance fund, in exchange for which he is entitled to legally established aid. The provider of aid (for example, the institution or group home for mentally handicapped) is paid directly from this insurance fund. This payment is primarily based on a tariff which is determined separately for each service.

TABLE 1:
Services for the Mentally Handicapped (1986).

Types of facility	Number	Clients
Group homes	500	12,000
Group homes for children	19	500
Daycare centers (adults)	183	8,400
Daycare centers (children)	103	3,900
Institutions	85	28,000
Short stay homes	7	300
Schools for learning disabilities	115	7,900
Sheltered work		23,900
Supported housing		700
Social Psychopedagogic Services	55	36,000

Source: FIAD, 1987.

The five first services for mentally handicapped mentioned in Table 1 are paid directly from general national insurance. With more than 4 billion Dutch guilders, about 10% of all money to inpatient and sheltered health care facilities is spent on care to mentally handicapped. The other services are subsidized by the Ministries of Welfare, Health and Cultural Affairs, education; Social Affairs.

Recent History

In the Netherlands, the process of separation of residential settings for psychiatric patients from settings for mentally handicapped was mainly initiated after World War Two, although some mentally handicapped people were still admitted to psychiatric hospitals in the 50s and 60s (Haveman, 1981). In 1988, about 1,000 mentally handicapped people were patients of psychiatric hospitals. Most of them have a mild mental handicap as a primary or secondary diagnosis, and are admitted for observation or treatment of serious behavioral disorders.

Until the 1960s, mental handicap was often seen as a serious illness which had to be treated by physicians and nurses. Consequently mentally handicapped persons were called patients. In many instances the institutions were located in rural areas. Beginning with the 1960's, mental handicap was considered as a developmental disability. As a consequence more and more attention was paid to

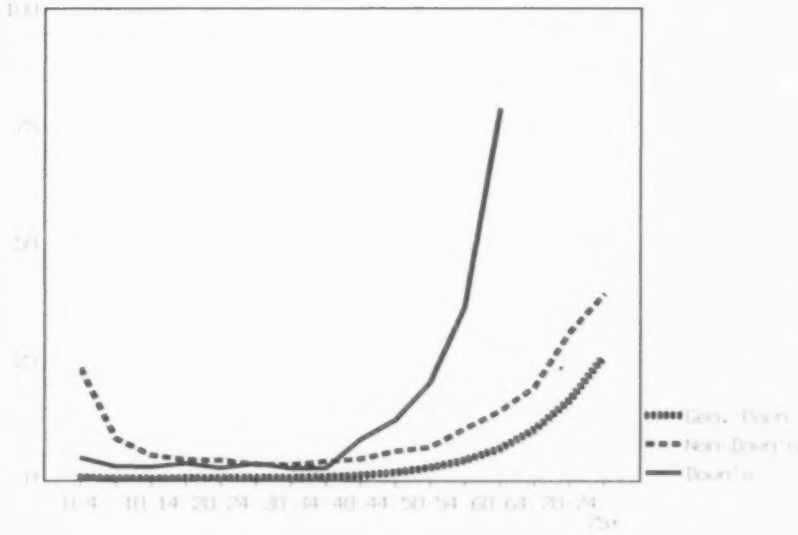
the development and education of mentally handicapped persons. Psychologists, educational specialists, music therapists, physiotherapists were appointed to develop skills and to educate. At the same time, small-scale facilities as group homes and day care facilities were built in the midst of the local community.

The service system is organized on a regional level. Within the general outlines of the Ministry of Welfare, Health and Cultural Affairs, the Provinces plan and administer the number and type of services needed. Each region provides a comprehensive range of services for mentally handicapped people and their parents. The cooperation between the various facilities are formalized within regional corporations.

Life Expectancy

At birth a child has a life expectancy of 76 years. The figures for the year 1987 show that women still live longer (79.2 years) than men (72.4 years). Because there are no such longitudinal data available for the mentally handicapped, little is known in our country about life expectancy of these Dutch citizens. The only data in this respect are from a National inpatient register. The age-specific mortality rates for the Dutch population, and institutionalized Down's and non-Down's syndrome persons are shown in Figure 1 (Haveman *et al.*, 1989).

Figure 2. Six-year age-specific mortality rates



These figures confirm the results of other studies showing high mortality for people with Down's syndrome over the age of 40.

Number of Elderly Mentally Handicapped

In estimating the prevalence of mental handicap in our country, studies were carried out in 1969 (Jansen), 1974 (Verbraak) and 1987 (Maas et al.). In the most recent study (Mass et al., 1988) all residential, halfway and outpatient services/programs for mentally handicapped were contacted in representative regions. In addition, mentally handicapped persons in special schools, mental hospitals and centers for persons with cerebral palsy were also traced. Since these studies were based on agency contact the figures do not represent 'true prevalence'. However the extensive use of the services in our country makes it likely that the results are fairly representative for all but the mild and borderline categories. A restriction to be noted is that the very young (0 - 3 years) and the very old (>70 years) were excluded.

Table 2: Number of mentally handicapped (x 1000) in the Netherlands, year 1987.

Number of persons age	severe	mild	total
4-17 years	13.5	15.8	29.3
18-49 years	29.6	29.7	59.2
50-70 years	5.3	4.0	9.3
Total	48.4	49.5	97.8

Source: Maas, Serail & Janssen; 1988.

The figures of Table 2 indicate that the number of elderly (50+) who become visible within the service system is still small compared with the other age groups. About 9,300 elderly mentally handicapped are in some way on the records of the service system.

The next question, consequently, concerns the type of service given to the elderly persons. Are they mainly clients of twenty-four hour, halfway or outpatient services? Statistics from the Dutch office for Social and Cultural Planning give us some information in this respect (Table 3).

Nauta et al. (1990) estimated that about 12,300 clients use more than one of the facilities, listed in Table 3. The total cost of these services to the mentally handicapped was in 1987 about 4.4 billion Dutch guilders (1 guilder = .54 US $). The services in institutions and group homes represented, with 49% and 13% respectively, a sizeable proportion of the total budget. The outpatient services, the social pedagogic services, were not included in this cost-calculation. These services involved most of the clients but used only a small part of the budget (1987 = 57 million guilders).

Table 3: Number (x 1000) of mentally handicapped persons within the service system; by age and type of facility in year 1989.

type of	age	facility
0-49	50+	all
residential full-time - institution for mentally handicapped		
24.8	5.1	29.9
residential part-time - group home		
9.6	3.0	12.6
daycare facility - daycare (age >18)		
9.0	1.3	10.3
daycare (age <18)		
3.7	0.0	3.7
education - school for slow learners		
16.3	0.0	16.3
school for very slow learners		
7.2	0.0	7.2
work - sheltered workshops		
19.9	3.0	22.9

Source: Nauta, Puijenbroek & Schoemakers-Salkinoja; 1990.

Care System for the Mentally Handicapped

There is no special policy for the care of elderly mentally handicapped. Their services are integrated within the service system for mentally handicapped in general.

Generic Services

Elderly persons with minor developmental disabilities are usually dealt with by generic services. Even if they are retired, unemployed or incapacitated to work, they are entitled to the same services from compulsory insurance (Ziekenfondswet) and the limited general national insurance (AWBZ) as other citizens. They get the same provisions from hospitals, specialists, physiotherapists, dentists, home help services, general practitioners etc.

While severely and profoundly mentally handicapped elderly persons have the same rights, most of them do not live on their own or with parents. In the majority of the cases, these individuals receive specialist services, e.g. group homes, institutions, social psychopedagogic services and social work, (nursing) staff, psychologists, special educationalists and physicians of these facilities. This personnel are employees with a permanent or temporary appointment and are experienced and trained for services to mentally handicapped individuals.

With the exception of dentists, physiotherapists and acute hospital treat-

ment, generic services have little involvement with severely and profoundly mentally handicapped elderly persons. There is, for example, no special policy in detecting and treating gerontological problems by general practitioners, because most of them do not work in a group home or institution and are not confronted with medical problems of elderly mentally handicapped with their special needs.

Social Psychopedagogic Services

Apart from general services given by social workers, district nurses, general physician and home-help facilities, there are specialized ambulatory facilities for mentally handicapped persons and their parents: the "social psychopedagogic" services. Each of the 55 social psychopedagogic services is responsible in its region for the provision of services to mentally handicapped clients and their caretakers. The tasks of consultation, information, support and referral of clients are done by 500 social workers.

Eighteen of these 55 services are part of a corporation, additionally operating day care facilities and group homes. About 34,000 mentally handicapped clients received help from social psychopedagogic services in 1986. In Table 4 some information is given about age and degree of mental handicap of these clients. About 2500 of the clients are older than 50.

Table 4: Client Characteristics of Social Psychopedagogic Services (1988); N = 36 000.

Age	
0- 5 y	6%
6-12 y	15%
13-30 y	47%
31-50 y	25%
> 51 y	7%
Level of Handicap	
mild	47%
severe	30%
profound	20%
otherwise/not known	3%

Source: SOMMA, 1990.

Day Centers

Necessary conditions of entry into day-care programs are that the person has some social skills and that integration in society is feasible. On the other hand, the clients must have a sufficient degree of handicap that they cannot function well,

for example, in adapted work settings and sheltered workshops. The clients of day care facilities live with their parents, other family members or in group homes. The main goal of the day programs is the improvement or maintenance of skills and level of social integration. Attention is given to household activities, manual skills, musical training and physical exercise. Furthermore, speech development and self care of the clients are stimulated. The programs at the 285 day care facilities were attended by some 14,000 mentally handicapped in 1989. About 1300 of them are over 50 years of age.

Group Homes

Group homes normally house 15 to 25 persons, over the age of 18 years, split up into groups of six to eight persons. They offer long-term sheltered housing and support to the residents. The group homes are built like other houses in the street, the residents being encouraged to participate as much as possible in the immediate community (street, neighbors, shopping and so on). Several group homes have some smaller housing units. They are connected with the group homes, but are separate units to allow more independent living for about four residents. These smaller units facilitate good possibilities for social integration.

During day time, people leave their home to work in sheltered workshops or on adapted jobs in industry, trade or local government. Other residents attend day care facilities. As a result, it is rather quiet in the group homes during the day, although there is an increasing number of house- bound old people in these facilities. There are currently 12,600 in about 520 group homes, However, about 21% of the residents are 50 to 65 years of age, and 5% are older than 65.

Until recently, basic ADL and social skills were a prior condition of staying in group homes. This precondition is now handled with some flexibility by service providers and the executing agencies for health insurance. Because of the increasing number of persons of old age with health problems, the National Council for Public Health (1991) recently advised the Secretary of State to cancel this precondition for staying in a group home. In the same report it is stated that obligatory full-time participation of elderly fragile persons of group homes in daycare facilities is in many cases not possible and desirable.

Because of the physical frailty of some elderly individuals, it is the policy of group homes to prevent transfers of older residents as much as possible. In practice, however, the actual accommodation is often not adequate to deal with the problems of these clients. Most residents have their own room, but it is in most instances on the first floor and not accessible by wheelchair, elevator or chair lift. There is no special room for the general practitioner or team physician on the ground floor, and there is no bed for persons who are treated in an outpatient clinic or are discharged from hospital. Trained nurses are scarce in these facilities.

In some districts, group homes and institutions jointly operate specially adapted daycare facilities for physically handicapped elderly, but an official line of policy in this respect is still missing.

While some institutions for mentally handicapped people have their origins at the beginning of this century, most of these facilities started in the 60s and 70s. Nowadays about 30,000 live in 98 institutions. These figures show that the institutions are much bigger facilities than the group homes, having a mean number of residents of about 300. The biggest institution houses more than 1,000 mentally handicapped individuals.

As a result of the development of community facilities over the past 20 years, changes have occurred in the pattern of admission and discharge, and hence of the characteristics of the residential population. In recent years only the more seriously handicapped, both mentally and physically, were admitted while the higher functioning residents were discharged to group homes. As a consequence, it is now only the more seriously handicapped who remain in the institutions. Only people who need day and night medical and nursing care, or have serious behavior problems, are now eligible for these facilities.

The residents of institutions live in groups of eight to fifteen persons. Each living-group has its own housing unit: the pavilion. Most of the institutions in the Netherlands are built as a complex with decentralized pavilions. Life in the pavilion is made as far as possible like a family home. Some of the residents attend sheltered workshops, but most of them have activities on the grounds of the facility. Most staff members on the living-groups are certified nurses with special training. In the institutions the staff /resident ration is very high - about 1:1. The staff on the groups are coached by physicians, psychologists, and remedial educationalists, as well as physiotherapists and speech therapists. Some of the residents attend sheltered workshops, but most of them have activities on the grounds of the facility.

Most institutions also have their own group homes located within the local community, housing small groups of four to ten members. In the last mentioned case, for example, two houses are connected. Overall, about 1,500 "residents" of institutions are actually placed in such group homes.

The age structure of these group homes is mixed, there being about 5100 residents over 50. The policy is for them to remain with their living group as long as possible. Only if it is practically not possible and if they become highly dependent on nursing and medical care, elderly persons are transferred to a pavilion with intensive nursing and medical facilities.

Generic Versus Special Services For The Elderly Mentally Handicapped

The increasing social integration of people with mental handicap has consequences for primary health care providers such as general practitioners, physiotherapists, district nurses, home helps and dentists, since they have more frequent contact with elderly mentally handicapped clients. It is the formal policy in our country to stimulate this process of community integration and normalization (Ministry WVC, 1983; 1990), but the progress is slow.

While most of the mildly mentally handicapped elderly live in society at large, only a small proportion of severely mentally handicapped elderly persons are served by community centered facilities. The experience of generic facilities servicing more severely handicapped elderly persons suggests that many of those service providers need help and advice from experienced professionals working in specialist mental handicap services.

From the point of view of residential provision, the existing nursing homes and senior homes for elderly Dutch citizens are in most instances not considered suitable to take care of mentally handicapped people with syptoms of old age. In a recent advice of the National Council for Public Health (NRV, 1991) it is stated, also, that the idea of setting up special nursing homes and senior homes for the elderly mentally handicapped should be rejected. Rather, the necessary differentiation of services for the elderly mentally handicapped must be planned by and within the mental handicap service system.

For comprehensive services (medical, psychological, social, financial) an active service policy is needed with a central point of coordination and responsibility. Parents obviously cannot remain indefinitely in the primary care-giving role - society must take the responsibility for providing appropriate services.

The current government view on provision of care to the older client group is explicitly expressed by the National Council (1991), as well as in general outlines in a governmental paper of the Dutch Ministry for Social Welfare, Public Health and Cultural Affairs (1990) about planning services for aged citizens:

1. For elderly mentally handicapped persons living alone or with others at home, health problems and problems with ADL should be resolved as much as possible by the generic services of primary care (outreaching and within the community setting) and by general hospital services.

2. If necessary, complementary measures should be taken for elderly residents at home, or part-time clients of group homes, daycare facilities or living groups in institutions. In this respect consultation with appropriate professionals,

and alterations in the physical environment are mentioned.

3. If the option to remain in the current residence is no longer possible, placement in special living groups for the elderly in group homes and institutions should be considered. Because of the ageing process, some group homes will become automatically senior homes in the near future.

4. If age-related infirmity is still greater, care-intensive small scale residential services for the elderly should be acquired under the shared responsibility of group homes and institutions.

5. In the most extreme cases of functional loss or medical problems, intensive nursing and medical services should be given in intensive care units (pavilions) of institutions for the mentally handicapped. The placement of elderly mentally handicapped persons in generic nursing homes together with demented elderly individuals is not considered an appropriate placement.

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CHAPTER NINE
A Perspective From Singapore

by M.K. Wong

National Background

Singapore is located at the southern tip of the Malay peninsula. Its geographic location: 136.8 km north of the equator, at latitude 1015'N and longitude 1040E. Long a British colony, Singapore became internally self-governing in 1959 and became an independent republic in 1965. The Republic consists of the main island (41.8 km long and 22.9 km wide) and some 57 small islands, giving a total land area of 633 sq. km (244.4 sq. m.). The Republic is headed by a President and governed by a unicameral Parliament and the Cabinet, comprising the Prime Minister and his Ministers. The GNP per capita is S $21,700 (slightly over US $12,000) in 1990. The infant mortality rate is 6.2/1000 for 1990. The literacy rate is 90.1% while the life expectancy is 72.1 years for men and 76.8 years for women.

The population comprises (1990 Census) 77.6% Chinese, 14.2% Malay and 7.1% Indian, this latter group including persons originally from India, Pakistan and Sri Lanka, and 1.1% Other Races.

Factors Contributing To The Problems Of The Older Individuals

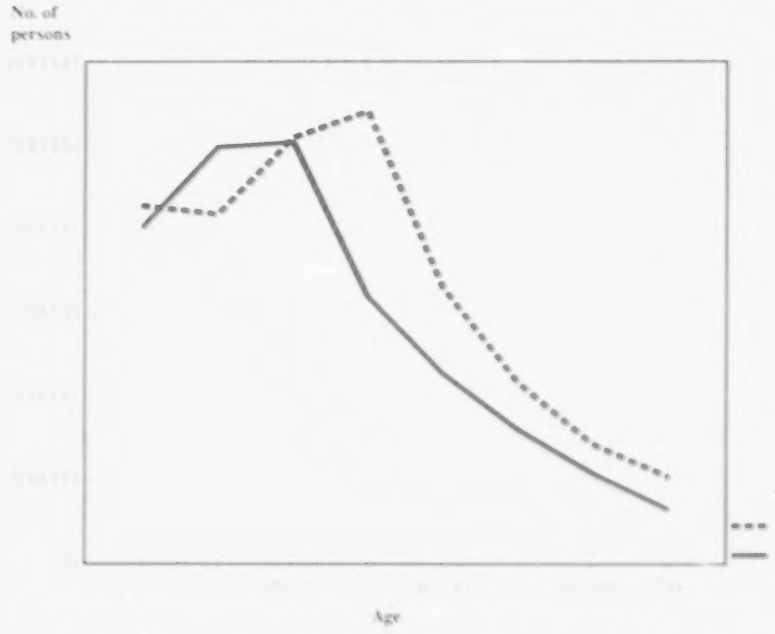
Like Japan and most countries in the West, it can be seen that the demographic trend in Singapore indicates an increasing proportion of elderly people, this trend being due both to a decline in fertility and mortality rates and an increase in life expectancy. As a result, there is a growing concern not only about caring for an increasing number of the elderly persons, but also a diminishing number of care-givers. The problem is compounded by the rapid social and economic transformation of Singapore. Urbanization, resettlement, development of new towns, higher education and full employment including employment of married women have each contributed to the break-up of the extended family system.

Traditionally, in most Asian societies, the elderly live with the family and very rarely in old people's homes. Urbanization has resulted in the resettlement of large sections of the population from the old shophouses, row-houses and kampong (village) houses, into new townships to live in high rise housing units. Large extended households with many families living together under one roof have been split up into nuclear families, each staying in their own flats often in different housing estates many miles apart. In the past, closely-knit families in clusters

formed kampongs and rural communities. Many such families had been friendly for generations and lived together as good neighbors. They helped to care for one another in times of need. They have now been separated and dispersed to different housing estates where neighbors are total strangers. In the older estates, children have grown up, got married and moved into new towns with their own families, leaving their older folks behind. This has inevitably resulted in isolation of elderly persons.

Figure 1 shows the age structure of the population in 1980 and 1990. It can be seen there is an increasing proportion of people in the upper age ranges.

Figure 1. Population age structure: 1980, 1990



Indeed, it is projected that the proportion of aged (60 and above) will increase from the present 9.1% to 11% in the year 2000 and 20.5% by 2030.

General Background To Welfare Services

The Government's philosophy on services to older persons is aimed at encouraging and assisting aged persons to live with their families and in the community. Admission of an aged person into residential care should only be a

last resort.

At present, there are 71 homes for the aged made up of 3 Government Welfare Homes, 43 Voluntary Homes and 25 Commercial Homes. (Table 1)

Table 1, Bed Capacity of the Homes for the Aged

Type of Home	Number	Bed Capacity
Government Welfare Home (See Table 2)	3	843
Voluntary Home	43	2,557
Commercial Home	25	954
Total	71	4,354

Government Homes

The Ministry of Community Development runs 3 Welfare Homes for destitute persons under the provision of the Destitute Persons Act as shown in Table 2.

Table 2, Type of Residence in Government Welfare Homes

Name of Home	Type of Residence
1. Woody Lodge	Beggars and vagrants, majority are non-aged.
2. Pelangi Home	Mentally burnt-out destitutes, majority are non-aged.
3. Woodlands Home	Aged destitute and some non-aged female destitutes.

Voluntary Homes

The 43 Voluntary Homes consist of:-

- 17 Community Homes which admit only the ambulant aged for day care.
- 22 Voluntary Welfare Homes. Only 11 of them provide residential care for semi-ambulant and non-ambulant cases.
- 4 Temple Homes admit only the ambulant aged.

Commercial Homes

The 25 Commercial Homes are profit-making organizations. They take in cases which do not qualify for admission into Government and Voluntary Homes, such as the aged who have family members/relatives and the non-aged who require nursing care or are intellectually disabled. Many of the residents in the Commercial Homes are semi-ambulant or non-ambulant.

Apart from the homes, there are many Senior Citizens' Clubs organized by the People's Association, Residents' Committees, Citizens' Consultative Commit-

tees and Voluntary Welfare Organizations which provide social-recreational activities, keep-fit exercises, etc.

Table 3, Community Based Senior Citizens' Clubs Name of Organizers Number of Centers and Number of People Served*

1.	People's Association	88	62,353
2.	Residents' Committee	143	16,774
3.	Citizens' Consultative Committees	9	3,679
4.	Voluntary Welfare Organizations	4	1,361

* It is possible that many of the aged may belong to more than one of the clubs above.

The Ministry of Community Development runs a Befrienders' Service where volunteers befriend, advise and assist lonely senior citizens; act as point of contact in times of crisis.

General information On Services To Persons With Developmental Disability

The stated philosophy of the Government is that, as far as possible, it will not provide any services directly, but will assist and encourage such services to be provided by the community or by voluntary organizations. Thus, the mushrooming of services by voluntary organizations, People's Associations, Residents' Committees, Citizens' Consultative Committees, etc.

There are two voluntary organizations, i.e. Association for Educationally Subnormal Children and Movement for the Intellectually Disabled of Singapore which were formed with specific aims and objectives to serve the intellectually disabled.

Generally, the younger group of people with developmental disabilities can attend the various "sheltered workshops" organized by Movement of Intellectually Disabled of Singapore (MINDS), Association for Educationally Subnormal Children (AESN) and Asian Women Welfare Association (AWWA) etc. They spend their time doing sub-contract work (simple assembling tasks) or getting training on social skills, work habits and basic literacy. The older group are probably staying at home although they are not excluded from attending the various "workshops". It is likely that a number of them are attending with or without their family members the various activities organized by the Senior Citizens' Club mentioned in Section IVC and Table 3.

Level Of Awareness Of Needs And Problems Of Older DD Persons By Policy Makers And Service providers

In the last 10 years, the government has set up at least two committees inquiring into the needs and problems of the aged in general. The first, the Committee on the Problems of the Aged, was appointed in June 1982 with the then Minister of Health, Mr Howe Yoon Chong, as Chairman. The second was the Advisory Council on the Aged in 1988 chaired by Dr. Ee Peng Liang, the Chairman of the Singapore Council of Social Services.

The terms of reference for the first Committee in particular were very wide ranging covering areas like attitudes toward old age, to making recommendations in work situations for older workers. The publicity given by the press, TV and weeklies before, during and after the proceedings of the two Committees were generous, to say the least. It has focused the attention not only of the public but also policy makers to the needs of older persons.

A case in point is the income tax relief. The Government has given income tax reliefs for any tax payer for maintenance of his or her dependent parents, grandparents or great grandparents if the dependents fulfilled certain age, level of handicap and financial criteria. The amount of relief for each such dependent is $3,500.

Similar reliefs of $3,500 can also be claimed for maintaining one's own/ spouse's handicapped brothers or sisters living in the same household. The main objective of such legislation is to encourage families to care for their aged and the handicapped.

The other recommendation was the extension of retiring age from the previous customary age of 55 years to 60 and later to 65.

Descriptions Of A Residential Service - Tampines Home

I quote from a volunteer, Mr. Andres Bennett, a staff member of the United World College of South East Asia (UWCSEA) who wrote in the Newsletter of Tampines Home, August 1991 issue. "In 1981 Tampines Home was housed in Lorong Buangkok in a pleasant rural setting of kampongs and coconut trees. However, the building was considerably less impressive and on a wet day with the rain beating on the corrugated zinc roofing and the storm water gushing through the holes in the rusted pipes, the environment was gloomy."

"Ten years on and the residents live in a different world; the buildings on Thomson Road are of the highest quality with extensive facilities and the highly skilled staff can offer the residents the opportunity to develop a significant degree

of independence and to make the most of their increasingly apparent talents. Chuan Seng now sits up and responds to the world around him rather than staring blankly at the ceiling from his bed; Mary, Huat Meng and Letchimie go to work and have developed far more maturity and confidence. Malika has learned to do puzzles and to communicate more effectively".

Tampines Home is a residential home run by the Movement of Intellectually Disabled of Singapore (MINDS) with 65 residents and 14 day-care clients.

Current Problems And Future Service Developments

Services for older persons with developmental disability must be a tripartite responsibility involving the family, the community and the Government.

The Government's policy is aimed at encouraging and assisting older persons to live with their families and in the community. Residential care should only be considered as a last resort. To this end, the Government has announced recently that it is setting aside $25 million to help charitable organizations to set up new homes or to expand existing ones for the elderly. It has also recently announced an increase in the quantum of financial assistance it provides in the building of such homes from 50% to 80%.

On the community level, activity centers are sprouting up in various community centers of housing estates where older citizens can get their daily exercise (some staffed with physiotherapists) and other social activities. In one of the estates (Simei Estate) the senior citizen club converted one of the void decks into a sitting room where one can meet older persons over a cup of coffee or a game of Chinese chess.

For those who are house-bound, a new Hotline for the Elders (Tel: 3538633) has been started by SAGE (Singapore Action Group of Elders) manned by volunteers for those who are unable to attend any of the activities but wanted to talk to someone.

The URA (Urban Redevelopment Authority) has an ambitious plan to increase the average living space per person from the present 20 sq. m. to 30 - 35 sq. m. in the next 10 - 30 years to improve the quality of life of Singapore citizens in spite of limitation of land.

All in all, it is expected that future development of services to older DD persons are going to not only increase in numbers, but also increase in varieties.

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CHAPTER TEN
Conclusions

by Steve Moss

In drawing together the various themes presented in this monograph, it is clearly necessary to take account of the differing social structures and philosophies of welfare which provide the background to the provision of services to older persons with developmental disabilities. In the nine countries represented in the preceding pages, there are three philosophies of service welfare which predominate. These may be referred to as the Asian, Western European and North American/United Kingdom models. In the far eastern countries, i.e. Indonesia, Japan, Singapore and Hong Kong, there has been a long history and tradition of family care through the extended family. Younger couples have been expected to look after their aging relatives, whether developmentally disabled or not, and social welfare provision has been geared to supporting families to do this. Generally speaking, these countries have not had a history of large institutions, and hence show no major drive to deinstitutionalization.

The "Western European" model of care, represented here by The Netherlands and Germany, has had, and continues to have, a strong accent on institutional care. While there is certainly evidence of the development of community services in these countries, institutional care remains an important option, although these institutions are becoming increasingly involved in the community. In some cases, reference has been made to clusters of houses within the community, linked to a central institution. The "North American" model is perhaps inappropriately named since it also includes Australia and the United Kingdom. These countries are clearly linked by a strong philosophy of normalization and deinstitutionalization. In Britain, this process is taken to its extreme, the target of the North Western Regional Health Authority, for example, being to move all people in residential care to ordinary housing units of about three people. Such a philosophy naturally has major staffing and resource implications.

Overall, the philosophy adopted by these countries is rooted in a belief that institutional care is fundamentally inappropriate for most people with developmental disabilities. From the viewpoint of the individual client, it is concluded from this philosophy that a more fulfilled life will result from a non-institutional pattern of care. At the same time, the philosophy is also making a more general statement about the ways in which the rest of society should view its developmentally disabled members. In comparison, the "Western European" model of care focuses more exclusively on what is believed to be the needs of the individual, and less on the general social message; the primary aim is to provide for the individual's needs by whichever method is most appropriate.

With regard to the general organization of services to persons with developmental disabilities, the majority of countries appear to have adopted a largely voluntary sector (private not for profit) organization, supported from government finance. Many countries also refer to the complexity of interaction between the various levels of service organization, local, state, provincial and national etc. Two representatives of the "North American" model, Britain and Canada, make reference to a development of private sector services. Indeed, Britain is currently undergoing a major reorganization of its traditionally local government provided welfare services, one aim of which is to foster the development of the private sector.

All countries have referred to the increasing urgency of making policy and service developments in relation to older persons with developmental disabilities. Despite the wide variety of economic and social characteristics of the various countries, all of them report a shift in the age structure of the population towards an increasing proportion of older people, with a consequent growth in the numbers of older developmentally disabled individuals. However, several countries have made reference to an absence of accurate figures on prevalence and to the large proportion of this age group who are "hidden" to service providers. As an extreme example of this, Hong Kong is reported as having 90% of its older developmentally disabled persons invisible to service providers.

All these countries therefore share a common problem in the need to address the problems presented by the growth in the number of older developmentally disabled persons. Also in common, however, is that none of these countries has a specific policy regarding service provision to this population. There appears to be a generally low level of awareness by professionals, although in some countries this now seems to be changing. A number of specific short- comings have been mentioned by the various authors, most of which relate to (a) lack of forward planning by families, (b) absence of suitable community residential provision which can adapt flexibly to potential loss of functional skills in old age, or (c) problems of providing suitable day service provision as people get older. In Germany, for instance, reference has been made to the strong focus on economically productive activity in workshops, with a consequent restriction on the proportion of time that service providers can spend in developing other skills relating to education and leisure.

A more general problem is faced by the Asian countries, namely, the major changes which are occurring in family structure. As mentioned above, younger couples have traditionally been responsible for the care of their aged relative. Nowadays, however, there is an increasing expectation that women should have the opportunity to develop a career. This, coupled with increasing mobility and break-up of the extended family, has led to a situation in which there are fewer informal carers available.

One major issue which is obviously of central concern to all these countries is the extent to which generic elderly services are appropriate for people with developmental disabilities. Although the United States is not specifically represented in this monograph, it is probably well known that this is a country in which some of the principal service developments have been devoted to the integration of people with developmental disabilities into mainstream senior services. Within this monograph, Canada makes specific mention of a demonstration project along these lines.

In the United States, experience has suggested that the use of generic services poses problems both in relation to the attitudes of existing non- disabled service users, and in terms of the lack of experience of generic service providers in dealing with developmentally disabled individuals. Experience in The Netherlands appears to support the second of these points; persons with mild developmental disabilities are accommodated within generic services, but more severely disabled individuals are not so successfully integrated. The authors make reference to suggestions which have been made that specific training should be available to generic service providers.

In Britain, the attitude amongst developmental disability services is generally that generic residential provision (i.e. residential homes for seniors) are inappropriate for persons with developmental disabilities. Indeed, our own research indicates that persons with equivalent functional status receive a poorer service in terms of individual programming, community involvement and leisure pursuits, than do persons receiving a service from specialist developmental disability services (Moss and Hogg, 1992).

Overall, the general feeling which arises from these chapters is that the development of services to older persons with developmental disabilities is still in its relative infancy. Although there is an increasing awareness of the need to cater for the needs of this group, this has generally not been translated into policy. It seems likely that one of the reasons for the lack of firm policy is that the specific needs of this population are yet to be clearly elucidated. Certainly, the issues are not straightforward. Service providers are presented with the challenge of providing both strategic plans which will cope with the overall needs and characteristics of the population of people with developmental disabilities in their later years, and individual plans which are sufficiently flexible to meet the changing needs of persons as they age. In relation to persons with developmental disabilities, these two aims are definitely quite distinct. Strategically, service providers can expect to find a group of people who are relatively high functioning and in good physical health, compared with younger individuals. This is because selective mortality tends to remove those members of the population who are more severely handicapped or have specific neurological or genetic problems. For instance, one can expect that around 75% of persons with Down syndrome will die by the age of 50 (Moss and Hogg, 1992). This differential mortality will be more

marked if the service is catering mainly for severely and profoundly retarded individuals than if the service includes a large number of mildly disabled persons. Paradoxically, therefore, the greater the mean level of retardation of the service population, the more healthy and high functioning will be the older members of the population compared with the younger cohort.

While this differential mortality effect has major implications for the strategic planning of services to older individuals, the provision of services to individuals must nevertheless cater for the survival of some people who will be suffering from severe retardation, genetic abnormalities and age - related medical conditions. The challenge is to provide a service which can meet these individual needs in later life.

At the present time, research on this population (apart from the association between Down syndrome and Alzheimer's disease) has failed to demonstrate that this is a group with markedly different needs from other individuals in society. Indeed, for persons with moderate or severe retardation, it appears that the outlook is fairly good provided one survives into later life. For these individuals, functional skills and physical health tend to be high. We must ask the question, therefore, should we be providing specific services tailored to this group, and if so, what should these services consist of?

While research cannot at this time answer the question, I would as editor, like to close this monograph with a personal viewpoint. I am of the belief that the most important aspects of aging for most people are psychological rather than physical. While many people reach old age with no significant infirmity, all people undergo changes in their expectation, interests, and patterns of work and leisure activity. Kelly (1983) has drawn attention to the crucial role of leisure throughout the life span. His "core and balance" model draws attention to the fact that adults have a set of central activities, usually centered in or around the home, which persist throughout life. Such activities include interaction with other household members, reading and watching television, walking and play. Distinct from this "core" is a balancing set of more specialized activities which tend to shift and change throughout life, as roles, self images and opportunities change. Kelly found that, for older members of society, interaction and social support become the most important dimensions of leisure. Gerontologists have, unfortunately, often adopted an over-simplified "activity" model of leisure, in which the effective use of leisure has been estimated by counting the frequency or number of activities. Almost all people say that the leisure they value involves interaction with others, or the investment of effort to achieve mastery. "They may spend more time watching television, but they define themselves by and invest themselves in more intensive enjoyment" (Kelly *et al*, 1986, page 532).

With increasing age may come an increasing sense of vulnerability as one's physical and economic resources diminish. For persons with a developmental

disability, this vulnerability may already be present to a considerable degree. The problem for service providers is to support the individual to an increasing extent as they age, yet not make the client feel that they have no autonomy. Helping the older person to remain autonomous both in action and personal choice is thus essential. I would advocate this as a primary goal for policy makers and service providers working with this population.

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U.S. Commentaries

Bruce C. Blaney

Susan Frankel

Matthew P. Janicki

Louis Rouiiz

Marsha Mullick Seltzer

Evelyn Sutton and Ruth Roberts

Commentary

Bruce C. Blaney
Human Services Research Institute, Cambridge, Massachusetts

The Search for a Conceptual Framework

The papers in this monograph exemplify an international search for a conceptual framework through which to design social, economic and health care policies that are capable of supporting people with developmental disabilities in long lives of quality. For more than two decades, normalization has served as the predominant international policy and planning framework. Indeed, seven of the nine authors identify normalization as their national policy in the field of developmental disabilities. One of the key issues becomes, therefore, the question of the relevance of normalization to policy and planning efforts regarding adults with developmental disabilities who are living long lives.

In describing service patterns in the Federal Republic of Germany, Gottfried Adam notes, for example, that the principle of normalization would seem to call for "integrating the persons (older people with developmental disabilities) in homes for the general elderly." He rejects this option in favor of an individualized and flexible approach. Similarly Steve Moss, the monograph editor, explicitly rejects the use of generic elder services as undesirable owing to their inferior quality relative to services available within the field of developmental disabilities. Moss, then, is similarly advising against the use of service patterns that would seem to be called for by a normalization strategy, that is the utilization of services typically available to older adults. Moss and Adam are implicitly challenging the principle of normalization, if indeed normalization strategies rob us of individualization, flexibility and quality.

Dilemmas and the Role of Normalization

Based on a decade-long focus on issues of aging and disability, I have concluded that what is flawed is not the principle of normalization. Our dilemma as a field consists rather in our not widely recognizing that the norms, attitudes, roles and expectations, including especially human service patterns, toward people who have lived into their seventh decade and beyond are fundamentally devaluing. As Alex Comfort summarizes the social construction of the oldness role in the twentieth century: "Oldness" is a political institution and a social convention based on a system which expels people.... [It] is a political transformation which is laid upon you after a set number of years, and the ways of dealing with it are political and attitudinal. (Alex Comfort. (1976) A Good Age. New York: Crown, P.28)

The vision informing the field of developmental disabilities generally is one

of people, long excluded from the social mainstream, entering valued roles and relationships, including membership in their communities. Regarding people defined as "old", however, some professionals, especially in the US, are replacing that vision with notions of "supported retirement" that emphasize both role exit and absorption into various versions of dual, that is both age and disability-based, service system.

What appears tome to be lacking in Moss, Adam, and among my colleagues in the US is an analysis of oldness as a devalued role. Without such an analysis, one meanders in a somewhat chaotic, empirical sea, rejecting what is observably harmful such as institutionalization but also, inadvertently, fostering policies which create age-segregation. The key dynamics, though, remain obscure: Oldness norms, the typical social patterns and attitudes governing the experience of aging, are essentially harmful and inferiorizing. Duplicating those norms for people with disabilities, therefore, does not constitute the application of normalization; quite the reverse, the imposition of "oldness" norms contradicts the key outcomes identified by normalization, entry into valued social roles and relationships. The overall impact is the creation of a new and highly devalued role—the "elder DD" or the even more revealing label of "retired client".

In its approach to those people defined as "old", the field of developmental disabilities, therefore, confronts an historically unique challenge. For other age groups, replicating the normative has added social value to lives lived on the margin. But for those who have lived long lives, support to entering normative/oldness patterns and roles derogates people to an even lower status and subjects those so-labeled to an amplified and double jeopardy. So we require an explicit corollary to the principle of normalization to guide our planning and policy formulations regarding adults who have lived long lives. When social norms are themselves mainly devaluing, human service actors must reject the typical and seek instead to support valued processes and outcomes.

Adulthood, Not Oldhood: Toward an Adaptive Vision

In this instance, the standard against which to measure progress toward attainment of valued outcomes is unambiguous and was thoughtfully captured in Moss' discussion of the rationale in the United Kingdom for not utilizing age-segregative environments on behalf of people with developmental disabilities: "...it is clear that few agencies are regarding the needs of their older developmentally disabled individuals as being sufficiently different to warrant separate service provision. ...this does not represent a lack of interest in these individuals, but rather the view that they are better served within the framework of services to adults with developmental disability." Given the above analysis of oldness as a devalued role, Moss' view is even more compelling. Indeed, our organizing principle should be adulthood, not oldhood. We will not be able to create the

flexible, individualized and integrative supports of our vision in terms of the reified and devaluing abstractions of the "elderly", the "old" or the "old DD's". Those whom we are attempting to know and to respond to are first and foremost adults, who are living long lives. Just as "people-first" language has assisted us to experience the essential commonalties among people with and without disabilities, I am proposing that our field adopt "adult-first" language regarding people, who are victims of "old-first" language, in order to support a comparable experience of intergenerational commonalties and continuity.

Conclusion: Vulnerability and Opportunity

Within this analysis the nine countries represented here may be ordered within a somewhat different taxonomy than that suggested by Moss—along a continuum of both consciousness of the issues and current practice. Moss has the most developed critique of the oldness role and of pseudo-integration into age segregated services. He is also able to point to human service patterns that have consciously rejected congregative and segregative practices in favor of integration and individualization. Adam affirms an approach based on individuality and flexibility; lacking a critique of the unique dual devaluation operating in this arena, he remains vulnerable to supporting devaluing strategies such as segregation, role exit and institutionalization. Much the same could be said of Groeneweg from Canada; though he cites Dozar's *Project Inclusion*, in my opinion one of the most ideologically aware projects in North America in its commitment to and rationales for age integration, he does not communicate an understanding of either the oldness role or of policies that would clearly commit to and promote Dozar's direction. The remaining papers are distinguished by their genuine humility, all acknowledging that they have just begun to attend to these issues. These authors also write with a sense of urgency that an adaptive strategy must be consciously developed or far less adaptive practices will spontaneously unfold in response to growing numbers of people with developmental disabilities claiming national attention.

All the developing countries as well as Japan present an exciting platform for change, because not only have they not yet segregated people with developmental disabilities as old, they have also not yet embarked on a wholesale age categorization and congregation of people without disabilities. One has a sense of looking into cultures that are able to experience the commonalities of long lives lived by adults like us rather that their social distance from a "special population with special needs." So the exciting opportunity in the developing world is to build communities and support families rather to construct socially isolated systems of devalued people overseen by service professionals. In the best case, the developing world may be able to avoid the societal creation of oldness both for people with and without disabilities.

In conclusion, I am urging the nine authors and others committed to fruitful policy directions to become acquainted with the literature on the social construction of oldness as a devalued role. Our mission should not be to add yet another "them" to the world community but to discover ways, "attitudinal and political", to support our communities in including those of us (with and without disabilities) who are living long lives.

Suggested Reading on the Social Construction of Oldness:

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Commentary

Susan Frankel
Director, Social Data Center, University of New Hampshire

It is with great pleasure that I read this timely monograph on older adults with developmental disabilities. The monograph provides a comprehensive, international status report of the provision of services for older adults with disabilities. In his concise summary of the articles, Moss highlights the importance of differing social factors and philosophies in guiding arrangements of services to this population of older adults. The message is clear that little information is available on adults who are both older (over 60 years of age) and developmentally disabled.

This gap is particularly problematic for all countries in light of the increase in the population of older adults, including people with developmental disabilities, and rising costs of health and service delivery. As the number of older persons with developmental disabilities continues to grow, and funds to pay their care become more scarce, it will become increasingly difficult to meet the needs of this group.

It is apparent from these articles that development and implementation of policies regarding services for older adults with developmental disabilities are in the beginning stages. As Moss states, "the needs of this population are relatively unknown and therefore not clearly stated." The lack of information provides a unique opportunity to conduct research in order to improve our knowledge of aging and disabilities, and to develop policies that address the needs of this population. My comments focus on future research investigations in this area.

First, there is a critical need to obtain accurate information about the prevalence of older adults with developmental disabilities. Older adults with developmental disabilities represent a significant subgroup of the elderly population. Yet, despite strong inclinations in the United States for data collection, relatively little is known about the extent of developmental disability in this population.

To date, research on the extent of older adults with developmental disabilities has been inconsistent because of the limited sources of data. The most common type of study performed has been surveys of professionals who work with older adults with developmental disability. Information from these studies are based on whether or not agencies have had cases of older adults with developmental disability. In essence, these surveys provide information about the extent to which different service personnel are familiar with this population.

These assessments, however, do not include older adults who live with family and have not been brought to the attention of the service network. Resources are needed in which accurate and reliable demographic information can be collected about this population. Without this information, policies will, at best, be educated guesses and at worst, opportunistic political compromises.

My second suggestion is for researchers to obtain information about the living situations and daily experiences of older adults with disabilities by designing studies based on direct interviews. One obstacle to planning efforts is the lack of reliable knowledge about the quality of life and needs of older adults with developmental disabilities. Understanding the needs of this group is crucial for administrators, planners and practitioners, and for making recommendations regarding policy formulation to enhance the lives of older adults with developmental disabilities.

Moss, among others in the field, have expressed the importance of 'quality of life' issues for these adults, e.g. what are the daily experiences of older persons with lifelong disabilities. As researchers, we need to include interviews with older adults with developmental disabilities themselves. Attention should be given to issues such as characteristics of older developmentally disabled persons, their relationships and activities; facility and care provider characteristics; and program and service utilization and needs.

Research questions to address include:

1. How do race, social class, social circumstances influences the lives of older adults with developmental disabilities?

2. What problems do older adults with disabilities face? In addition, in what ways do these experiences differ by living arrangement, type of disability and age?

3. What are the transition experiences from work to retirement? Does the quality of life decline in retirement?

4. What day services are used and needed? What are the barriers to the use of available services and programs?

5. Based on study findings, what are important problems that must be addressed in enhancing the lives of older adults with developmental disabilities?

Research findings to these questions will offer exciting opportunities to reflect on the transition and life experiences of older adults with developmental disabilities. In particular, such research will allow the identification of a comprehensive research agenda worthy of immediate attention of both researchers and policy makers.

The third suggestion is for researchers and practitioners to work together in the design of research projects. In general, practitioners and researchers have been reluctant to work together. This hesitation is a result in part from shared misconceptions and stereotypes the two groups have about each other. Researchers often claim that practitioners know little about the research process, while practitioners claim that the research conducted is rarely relevant for the development and implementation of policy. In order to conduct research that is relevant to the development and implementation of policy, researchers need to include the voices of practitioners who work with older adults with developmental disabilities.

For researchers, practitioners provide crucial ideas and information about research they would like which would help them with their work. For practitioners, researchers have access to research findings that have important implications for their work and can inform policy decisions. It seems clear that greater cooperation will be advantageous to researchers, practitioners and the public in general.

This monograph highlights the intersection of aging and disabilities. In order to be most effective and responsive to the needs of this population, we can bring the voices of older adults with developmental disabilities and their advocates to those in the academic community who conduct research or help fund it. In addition, their voices will provide researchers with topics for future research that have meaningful and practical application, especially for policy makers.

Commentary

Matthew P. Janicki
New York State Office of Mental Retardation and Developmental Disabilities, Albany, New York

One of the most telling aspects of this compendium of international stories is that with services for older people with mental retardation there may not be any universal truths. Moss and the writers who have contributed to this text show that much of what is done within each nation is very much a reflection of that nation's heritage, culture, values, and economic resources. Many nations, less industrialized than some among those of the first world, maintain extensive family networks that provide the natural supports for family members whose conditions may foster dependency and a need for special care. Others, have mastered the means to provide surrogate services that mimic or replace the natural supports often provided by extensive family networks. Others practice segregation in congregate housing, either when, to their detriment, economically or programmatically it is no longer viable or warranted or, to their credit, such segregation provides the only hope for special care and survival.

Moss notes the variability of approaches taken to address old age. Some of the approaches presented show forward planning that has begun to incorporate recognition of lifespan issues and the need to modify services contingent upon changes related to age. Others practice benign neglect, relegating the aging process to the same offerings given to other aged persons. Some have developed extensive housing programs that become the focus of all activities as their residents age in place. Others try to promote the varied daily routines that offer the opportunities to live ordinary lives, with both the resulting positives and negatives.

Other approaches are evident as well. Some have begun to differentially address both third and fourth age issues, others merge the two with a common response. Some have recognized the value of age peer programs and have sought out means to effect social integration and inclusion among all older persons without discrimination and rejection. Others argue that melding persons with disabilities who are older with others who are older is demeaning without considering the value of age peer friendships and companionship. And then there is the reality that many nations have not the economic or personal resources to debate philosophical purity in providing for needs, when the basics of life expectancy, health, and just survival are paramount issues. Aging may in the end be a luxury, one that reflects the nature of the greater society and the commitment to its peoples and its survivors.

With the exception that we need to know more about the aging process, the aging of persons with disabilities ought not receive more or less attention that the

aging of any other group of individuals. Certainly, there are exceptions, one in particular is when the disability impairs normal aging and indeed may lead to lessened life expectancy and damaged health. Examples include the aging of persons with Down syndrome (with its premature aging and increased incidence of Alzheimer disease) and the earlier age related debilitation noted among older adults with cerebral palsy and other neuromuscular conditions. Certainly, other exceptions become considerations as well. These include the differential means of looking at the aging related needs of persons with various degrees of mental and physical handicap. Another is the differential approaches given to third age needs and issues compared to fourth age needs and issues.

Perhaps the most obvious import of this collection of papers is that many nations are only now beginning to identify the aging of large numbers of their citizens with mental retardation as a social policy concern. Until recently, such aging was not a public concern, nor was it an issue among providers and families. Now, through the work of dedicated and interested workers, this phase of the lifespan has drawn more interest and is offering new and exciting opportunities for research, analysis, and advocacy.

It would be my hope that through this text readers will gain a broader perspective of the nature of aging and the variability of approaches being undertaken across the world. The lesson offered is tolerance and the ability to understand that service approaches are culture bound and heavily influenced by the nature of life around the persons involved. Certainly, the perspectives offered should guide those readers involved in shaping public policy and offer an appreciation of the varied means to address issues of particular relevance within their nation. Lastly, this text should help enlighten those of us whose primary commitment is to bettering the lives of persons with lifelong disabilities and permit us to understand and learn from the diversity of approaches extant that deal with common aging related issues.

COMMENTARY

Louis Rowitz
University of Illinois at Chicago

The United States is now completing almost two active decades of experience with the development of programs for older persons with a developmental disability. Parallel to this specific concern about older persons with a developmental disability has been a movement from a philosophy of primarily residential service and community exclusion to a model of services based on a community service model with complete inclusion. All the countries discussed in this monograph are dealing with similar issues. Yet, each of the countries presented offer some unique approaches to the topic and provide the American reader with a series of innovative interpretations that highlight and possibly will enhance some of the future programmatic developments in the United States. It is my intention in the next few pages to mention a few of these approaches.

Future Directions

Lifespan Perspective

There is a tendency in the health care and social service delivery area to view life as a series of discrete life stages. This is a mistake. Life is process and programming should be viewed in a dynamic process-oriented way. A lifespan perspective allows the policy maker and the service provider to plan services that are integrated and use past progress to plan future services based on present needs. The lifespan approach also looks at service as being provided within a family context. Thus, family concerns are primary since the person with a disability often spends a large part of his or her life within the family framework. The lifespan model also assumes that the individual will spend most of life within a community setting. A lifespan perspective allows us to view community integration concerns in a unique way.

Changing family structures

There is often a tendency by professionals and policy makers to assume that not only are all people with disabilities alike but also that all people live in traditional nuclear families. Families differ in form and shape. Programming needs to take these differences into account. Families are also dynamic and change as life impacts on them in different ways. Family dynamics are affected by where these families live (urban and rural areas), religious and ethnic differences, income differences, historical circumstances, political issues, and so on. The family does not simplify our planning efforts but rather makes the whole process more complex. There is a tendency in the United States and other countries in this monograph to ignore these differences and to attempt to simplify our planning efforts.

Community Care Management

The idea of case management is important if there is to be an integrated approach to service delivery for people with developmental disabilities. However, case management as an idea assumes a medical model rationale for the delivery of service. It is time to move beyond that kind of a rationale. If the preference is to promote a community integration model, the issue then is a community care approach. This means that we need a new term to better reflect our approaches. I propose that we talk about community care management.

As pointed out in the chapter on Germany, there is a critical need to have a comprehensive and yet flexible approach to services for older persons with developmental disabilities. A comprehensive approach means that all service options should be available as needed. Residential service models should not be excluded if these are the best service and most appropriate models available.

The Communication Issue

The lack of communication between families, service providers, and government agencies about types of services that are available was pointed out in the chapter on Australia. This seems to be a problem in many countries including the United States. Service professionals need training in communication skills and to learn how to relate to families. Laws, regulations, financing of services, service eligibility, and so on are very complex. If the service provider does not understand the nuances of these processes and serve as an intermediary between the government office and the family, it is not hard to understand the problems that families face in dealing with these issues and with service providers who do not simplify the process. A community care manager would be able to address these issues.

Separate or Integrated Service Systems

A major issue in a number of chapters relates to whether older people with a developmental disability should be treated within the aging services system, integrated into the regular health care system, or served within a special service sector reserved for the special needs of this population. The community integrationists would argue for complete integration into the mainstream health and service delivery system. It was argued in the chapter on Canada that community integration may guarantee service options for older persons with a developmental disability. However, this would be in contrast to earlier life stages where specialized services guarantee the service access. An important question must be raised concerning whether total integration provides the best models of care or not. These issues are also raised in the United States and are still not resolved. Financial issues may eventually resolve the controversy by determining what the government is willing to finance. Policy groups and other advocacy groups will have some voice in the eventual resolution if these groups become more active in influencing the lawmakers.

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A second issue of relevance here is whether the services will be given in the public or private sector. A number of the chapters talked about privatization but also raised critical funding issues. There seems to be some differences in how private services are defined and organized. The issue of profit also needs to be addressed. Discussion needs to occur about whether the government should be in the direct service business at all.

Permanency Planning

Parents are concerned about their offspring with a developmental disability after the parents die. These issues need to be addressed before it is too late. If the families are to be involved in the eventual decisions, they need to address them during their lifetime. The issues here are partly financial, partly oriented to the issue of guardianship, and partly oriented to guaranteeing a positive quality of life for the person with a developmental disability.

Disability Controversy

There is no consistency in the way that disability is defined internationally. The confusion partially relates to the fact that disability can be due to physical or cognitive deficits. Age at onset may affect how a specific problem gets defined. For example, mental retardation is supposed to show an onset prior to age 18, according to the American Association on Mental Retardation. The United States legislation on developmental disabilities says onset can occur up to age 22. Physical disabilities can occur at any age of the lifespan. It is also necessary to see the differences in diagnosis across international boundaries. In addition, the classification designation of mental retardation is not commonly accepted out of the United States. We need to be careful that we are talking the same language when comparisons are made. As pointed out earlier, it is also important to see disability as a heterogeneous phenomenon rather than as a homogeneous one. People are different.

It has been the intention of this commentary to point out a few of the questions and issues raised by this monograph. Cross-cultural comparisons are important for the similarities as well as the dissimilarities that they show. Our problems are similar, but our solutions have been different. This monograph helps us to better view what we do in the United States and to also open the doors to communication over national boundaries.

COMMENTARY

Marsha Mailick Seltzer
University of Wisconsin-Madison

While there has always been some interest in the aging of persons with developmental disabilities, since the early 1980's this issue has received a great deal of attention. Several trends have coalesced to increase the salience of this issue. For example, in the United States and in many other countries, the age structure of society is changing. The "greying" of the population in general has given rise to new services for elderly persons. In this country, professionals serving persons with developmental disabilities have become more interested in the special challenges that aging brings as well as the opportunities available for integration of older persons with developmental disabilities within the generic network of services for aging persons.

In the U.S., a great deal of progress has been made in establishing a firm foundation for serving older persons with developmental disabilities. Federal initiatives have targeted three major areas of activity: 1) incentives have been provided by the Federal government for collaborative efforts between the aging and developmental disabilities service sectors on the State level; 2) support has been provided to develop university-based professional training programs on aging and developmental disabilities; and 3) grants have been awarded to researchers to investigate the age-related changes manifested by older persons with developmental disabilities and their families.

The progress made in the U.S. during the past decade to develop initiatives in support of service, training, and research on aging and developmental disabilities is noteworthy. However, a great challenge remains in the implementation of these initiatives throughout the country. The problems facing older persons with developmental disabilities in the comparatively advantaged service context of the U.S. are very similar to the problems described in this monograph as characteristic of both industrialized and unindustrialized countries around the world. In recognition of commonality of these challenges, most of this commentary will be devoted to examining three obstacles to providing an optimal quality of life for older persons with developmental disabilities that emerged from my reading of this fine monograph.

Common Challenges

Stress on Family Caregivers

One concern that received attention in many of the chapters in this monograph was the high level of the stress experienced by elderly parents who continue to reside with a son or daughter with a developmental disability. In a few countries described in the monograph, these families try to hide their member with developmental disabilities out of shame and, consequently, some families

manage to avoid all contact with service providers. In most countries, however, families bear the bulk of caregiving responsibility primarily because the service system is not adequately funded to provide for all older persons with developmental disabilities in need of residential, vocational, and support services.

Although few data are available on the characteristics and needs of family caregivers, there is a general consensus that the family cannot be expected to carry out its caregiving function independently without support and assistance from the formal service sector. While this is not a new problem, the increasing size of the adult population with developmental disabilities and the prevalence of family-based care make it more compelling now than in the past.

Need for Residential Services

In a related vein, there is an international recognition that non-family residential placements are needed to support the development and well-being of some persons with developmental disabilities in adulthood and old age and to relieve family burden. In no country was this need considered to be unimportant. In the U.S., as in many of these countries, there are long waiting lists for residential services and inadequate resources available to meet the pressing needs. Interestingly, there was great diversity among the countries described in this monograph regarding the acceptability of large residential settings. As the editor aptly points out in his concluding analysis, there are large national differences regarding the balance of family versus out-of-home placements, large versus small placements, and the prominence of ideology versus individual need in determining the services that are offered. Nevertheless, in all countries the development of non-family residential placements was identified as a major unmet need.

Need for Accurate Data

In most every paper, acknowledgment was made of the need for accurate data about the number of older persons with developmental disabilities. In some locales (e.g., Hong Kong), there are enormous disparities between the numbers of individuals known to the service system and the numbers projected to be in the population, while in others (e.g., Germany), there is more confidence that the service providers are aware of nearly all older persons with developmental disabilities. The U.S. falls somewhere in between these extremes. The need for an accurate population count is accompanied by a need for an accurate description of the characteristics and service needs of older persons with developmental disabilities and their families. In countries with ample resources, an accurate data base would facilitate a rational allocation of available services and a sound basis for developing new services.

Areas of Diversity

In addition to these three areas of common challenges, there are marked areas of diversity that emerged from a reading of this monograph. For example,

social and vocational integration is easier to achieve in nonindustrialized countries such as Indonesia than in industrialized countries. This is because useful agricultural roles can be found for adults with more severe developmental disabilities. Population density also influences the service context, with locales such as Hong Kong, in which the living space available for each family member is very limited, having more of an institutional tradition than less dense environments. Other examples of diversity from country to country reflect the emphasis placed on specialized services for older persons with developmental disabilities as compared with an emphasis on integration with generic aging services.

These and other areas of common concern and diversity are highlighted in this monograph. A similar structure is used for each chapter, making it possible for the reader to compare and contrast all of the countries described. A productive international exchange of ideas is fostered by this document that will hopefully enhance continued development of services for older persons with developmental disabilities and their families.

COMMENTARY

Evelyn Sutton
with the assistance of Ruth Roberts (both are with the Rehabilitation Research and Training Center on Aging and Developmental Disabilities.)

Introduction

In the United States, there are few states that have regulated a retirement option for the constituency of older persons with developmental disabilities. In many states, services for adults are not as well established as those for children with developmental disabilities. It is only recently that the transition between school and work has been a focus of concern at federal, state and local levels. Concern about an aging population lags behind all the rest. Still, there is concern, as evidenced by the 7000 names representing all fifty states that comprise the current mailing list of the RRTC Consortium on Aging and Developmental Disabilities.

The National Older Americans Act as revised in 1987 includes persons with disabilities as a target population to be served. At the federal level also, the Administration on Aging and the Administration on Developmental Disabilities published a Memorandum of Understanding in 1989. It emphasizes training of aging and developmental disabilities staff to understand the abilities and unmet needs of older persons with developmental disabilities, and to improve services for this population. It also encourages linkages at state levels in the areas of program, advocacy and research.

Joint agreements between state departments on aging and developmental disabilities have been signed in the states of California, Illinois, New York, Massachusetts, Michigan, Virginia, Ohio, Pennsylvania, Montana, Connecticut, and Kentucky. These are gradually resulting in more effective training and programming activities for older people who are developmentally disabled and a growing history of cooperative activity among service systems.

While there are significant parallels in the programs described in this monograph, differences are also clear, reflecting different cultures and varying stages in the development of human services policy and practice across international lines. Nevertheless, a common agenda emerges, one shared also by the United States and in response to which the United States can continue to make a strong contribution.

As editor Steven Moss notes in a summarizing chapter, the common agenda includes such issues as 1) the development of a trustworthy demographic base, 2) raising the level of professional awareness about the aging process (and its competence in meeting the changing needs of older people), 3) provision of

programs and facilities that will maintain physical, social and adaptive living skills, and 4) expansion, encouragement and development of the autonomy of older individuals with disabilities.

This commentary will specifically address two of these agenda items and discuss contributions accomplished and in progress as a result of the United States government-funded Rehabilitation Research and Training Consortium on Aging and Developmental Disabilities. Seven universities representing six states are involved in the Consortium. The issues discussed below concern (1) staff development and (2) appropriate program opportunities.

Training of Specialists in Aging and Developmental Disabilities

In its work on behalf of older individuals with developmental disabilities over the past four years, the Consortium on Aging and Developmental Disabilities has taken the position that as long as people with developmental disabilities are participants in a system of services, their lives will not be benefited unless that system can change to meet their changing needs and interests. Consequently, researchers within the Consortium conducted intensive studies to identify the competencies and characteristics of a Specialist in aging and developmental disabilities. Such a professional, properly qualified and trained, would provide and manage the best and most appropriate services for older individuals with developmental disabilities.

Their research established six categories of competency, or six sub-roles of the Specialist. These competency areas demand special knowledge in gerontology and developmental disabilities, service planning, appropriate activities, staff development, advocacy, communication and community relations. A curriculum guide and other materials have been developed by the Consortium addressing all of these areas in depth. It is safe to assure that many hundreds of professionals and service providers across the United States have received some training in the specialist role.

Expanding Life Choices and Experiences

Many gerontologists, both researchers and practitioners, embrace an activity model in addressing issues of successful aging, as Dr. Moss points out in his statements summarizing the monograph. However, contrary to his argument, the activity model strongly implies a social component to maintain and develop social skills as well as physical and mental health and cognitive functioning.

Within the developmental disabilities community of elders, there appear to be two distinct levels of status and need. These differences emerge from what is known at present about this population, although all of the experts authoring this

monograph recognize the need for more specific data.

Descriptions of this population found in the (research) literature of the United States present a similar picture. So too does the general view of the general population of older persons, who are variously described as the well elderly and the frail elderly, the community elderly and the elderly in retirement/nursing homes, the well elderly and the at-risk elderly. Within these groupings, of course, there are endless individual differences. However, in addressing needs of the older population, the human services system generally targets its programs to the two larger categories of diversity.

Individuals with developmental disabilities have, on the whole, been described in much the same way throughout this monograph. Many appear to be very much like the well-elderly of the general population. Greater frailty seems to exist among those who are older or who have more severe levels of retardation. The activity model, with its focus on the maintenance of physical, intellectual and social functioning is applicable to all.

In 1990, researchers within the Consortium on Aging and Developmental Disabilities surveyed the content of "retirement programs" designed by county boards of MR/DD within the state of Ohio. They found that many people over the age of fifty-five were still at work in sheltered workshops. Whether by choice or because good alternatives are lacking is unclear. Among those who had reduced their work hours or were engaged in a full or part-time "senior" day alternative, the variety of activity options appeared very limited in this study.

The possibilities of discovery and development during the later years have been put forward by a number of noted gerontologists and social scientists. However, the imagination and creativity that can produce individualized innovative programming of high quality seem missing in this Ohio profile. Because of its national vantage point, the Consortium on Aging and Developmental Disabilities is well aware of programs underway in Colorado, New York, Mississippi and other states as well as in Ohio that are expanding horizons for aging persons with developmental disabilities. An increasing number of models exist which will, in time, find their way around the world to enrich the lives of the "well-elderly" with developmental disabilities and also of those with greater frailty.

The Consortium study found a strong example of such a model in the Ohio study. Almost fifty percent (50%) or 325 of the 595 individuals fully or partially "retired" were reportedly participating in community-based activities of various kinds. This appears to be a result of intensive awareness-raising throughout the state during the 1980's, as well as evidence of replication of the peer companion model of community access for older persons with developmental disabilities,

demonstrated at the University of Akron with funding from the Joseph P. Kennedy, Jr. Foundation.

The Consortium researchers also discovered a surprising lack of preparation for later life transitions provided for clients by the seventy-one agencies participating in the study. Among older individuals being served, too few seem to have a voice in their own futures. This finding has led to development of an innovative later life planning curriculum targeted to persons with development disabilities who are middle aged or older. Its core is presentation of an array of meaningful options for health maintenance, leisure activity, and residence, leading to individualized planning for later life. It emphasizes practice in choice, decision-making and self advocacy. Dr. Moss states in the final line of his summary: "I would advocate this (autonomy) as a primary goal for policy makers and service providers working with this population."

So say we all!

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•Diane E. Woods, Project Director, IEEIR
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